



Why People with Intellectual and Developmental Disabilities and their Families should support the expansion of the 1915b/c waiver to other LMEs in North Carolina

Response to the Position Paper of the Arc of North Carolina

Executive Summary

The Innovations Waiver is a 1915c waiver that has been operated by the PBH LME under contract with the Division of Medical Assistance for over five years. It operates concurrently with a 1915b Managed Care Waiver, also managed and operated by the PBH LME. This paper is a response to the recent Arc of North Carolina (Arc NC) position paper opposing the state's plan to expand, with amendments, the Medicaid 1915 b/c waiver operated and managed by the PBH LME.

National Healthcare reform expands healthcare services to the uninsured through an *expansion* of Medicaid. In North Carolina, estimates of the increase in numbers of recipients are as high as 50%. It is well known that Medicaid is on an unsustainable upward cost/utilization trajectory. Few, if any, states will be capable of participating in Medicaid without a sophisticated plan for managing services and containing costs. And:

- It is unlikely that individual health care sectors are going to successfully advance the idea that their constituency (e.g., cancer, Multiple Sclerosis, I/DD) ought to be exempted from managed benefit plans.
- It is unlikely that the state will be capable of financing separate benefit plans according to narrow or particular populations/sectors/specialties.
- If cost is not managed, it is unlikely that the state will be able to expand waiver services to the numerous people with intellectual and developmental disabilities that are on waiting lists, and North Carolina will continue to offer a system for people with intellectual and developmental disabilities that is comprised of the "haves" and the "have nots". I/DD waiver services are NOT an entitlement, and although we are unsure how services for the I/DD population will be addressed through Healthcare Reform, expansion of services for people on the waiting list will definitely be impacted by the availability of funding.

The Arc NC position paper implies an exclusive concern for families and consumers; however, the Arc, in addition to being an advocacy organization, is also a major Case Management service provider. It would seem important for the Arc NC to disclose to the public how the business (other than advocacy) aspects of its work would be affected by the b/c waiver environment.

There are 5 key reasons why the position of the Arc NC is incorrect and waiver expansion should be supported:

1. PBH has very specialized strategies and management systems in place for each disability served. The management strategies for the Innovations Waiver are designed specifically to meet the needs of individuals with intellectual and developmental disabilities and are implemented by professionals experienced and qualified in the field of intellectual and developmental disabilities.
2. The Arc NC representation of the b/c waiver as not in the best interests of families and consumers neglects the disclosure of its business interests. Arc NC is a provider of the Innovations waiver services including "Community Guide" for PBH and of "Targeted Case Management" for the CAP-MR/DD waiver. The earnings potential for providing Targeted Case Management far exceeds that of the "Community Guide" service. Arc NC, therefore, has a strong interest in maintaining the current system. "Care coordination," a systems management tool essential to this type of waiver, is a key function for the LME.
3. In these difficult economic times, it is imperative that the state use the best available tools to manage Medicaid costs fairly and equitably across the population served; the b/c waiver is such a tool. Without sophisticated management of available resources, we are on an unsustainable cost trajectory in all healthcare sectors, including in North Carolina's Medicaid system for people with I/DD. If the LMEs fail to become a public option for managing Medicaid, it is unlikely that I/DD services, or any other sub-population, would be "carved out" (separated from the rest of the Medicaid system) for its own particular management purposes because of the increased costs that would ensue. If the "behavioral health" (MH/DD/SA) funding strategy is at risk of being folded into the larger healthcare system and forced to compete for resources with primary care, hospitals, other specialty services, etc., expanding the b/c waiver is a way to ensure that the North Carolina MH/DD/SA system remains operated by North Carolinians and tailored to the unique needs of these populations.
4. b/c waivers increase the likelihood of an expansion of the number of waiver slots for people that are on the waiting list by efficiently managing limited resources
5. b/c waivers have strict quality requirements that ensure higher quality providers, while including assurances that consumers will have an adequate choice of providers.

There are a number of significant advantages in the design and operation of a b/c combination waiver that are delineated in the body of this paper. Additionally, we are attaching information to this paper that defines some of the most important outcomes achieved through the operation of the b/c waivers in the PBH catchment area.

Arc NC has stated that expansion of PBH operated waivers to other LMEs should be prohibited. The risks of failing to expand specialty waiver operations in North Carolina have been detailed above. Additionally, the Arc NC is not a direct stakeholder in any outcome of PBH expansion except to the extent that the expansion impacts its market share of case management service delivery. Expansion, collaborations and/or mergers of LMEs under any circumstances require extensive deliberations, evaluations, and negotiations by local stakeholders. Each entity must evaluate the pros and cons of any such endeavor and ultimately determine what is in the best interests of those it serves. Outside involvement does little to advance this evaluation process, particularly when inaccurate and misleading information is disseminated to people that depend on the public system for services. Beyond these matters of principal and process, PBH is utterly committed to investing in robust local presence and avoiding centralizing services and functions that need to remain local, regardless of any expansion.

Finally, based on the Healthcare Reform Bill, our system of services is subject to external influences that will result in vast and rapid changes in the general and specialty healthcare system in North Carolina. We should be working together to prepare for the advent of these changes and to ensure that the interests of all people with significant disabilities are addressed by the MH/DD/SA system of the future.

It is our hope that the Arc NC will reconsider its position in light of the larger circumstances rapidly coming our way with Healthcare Reform, the information presented herein and the success of the Innovations waiver demonstration.

What follows is a detailed response to the recent Arc of North Carolina (Arc NC) position paper opposing the state's plan to expand, with amendments, the Medicaid 1915 b/c waiver operated and managed by the PBH LME. Arc NC states that the waiver "is not in the best interest of people with developmental disabilities." In a companion document, the Arc NC also states as a key reason for its opposition that the b/c waiver will not well serve people with intellectual and developmental disabilities (I/DD) because services and financing for the I/DD population in the Innovations waiver are embedded in the larger MH/DD/SA system. Arc NC alleges that the cross-population b/c waiver has a bias that is "recovery" oriented (a mental health term) and advances an approach inappropriate for people with intellectual and developmental disabilities.

Considerations mandated by the Federal Deficit, State Government revenue shortfalls, and the rapidly evolving Healthcare Environment

Before going further, it is important to outline the broader contextual background for the PBH LME's response to the Arc NC position papers.

Like other states, North Carolina will soon need to develop strategies to incorporate the expanded Medicaid population that will be added through Healthcare Reform. The numbers of people that will be brought into the Medicaid system will tax existing agencies such as Departments of Social Services that enroll people into Medicaid, the adequacy of the entire healthcare provider system to meet this new demand for services, and the capacity of the state to manage Medicaid costs over so many people and providers. The scope of this Medicaid expansion alone will require North Carolina to consider new strategies to manage the Medicaid system. Additionally, North Carolina will be influenced by national trends that involve changing configurations of providers, and new models of reimbursement. The need to manage healthcare costs is essential to the success of Healthcare Reform. The rapid escalation of costs for healthcare services is not sustainable, with or without Healthcare Reform. Even with a higher Federal match for Medicaid, states will need to control Medicaid costs, which even today are exceeding state budget limits.

Medicaid coverage for people with incomes up to 133% of poverty and the elimination of categorical Medicaid is a major advantage for people served in the MH/DD/SA system. This will bring new resources into our system, and will strengthen MH/DD/SA specialty providers. We are not yet sure whether there will be expansions in services or payment for rehabilitative services (services needed for people with mental health and substance abuse conditions), or for habilitative services (for people with intellectual and developmental disabilities). However, the addition of any new resources into our system of services, will have indirect positive outcomes on the system at large.

The threat to the current MH/DD/SA system will come in the form of service and cost management expertise offered by large healthcare management corporations. States will be very tempted to move both the responsibility and the risk to such entities to protect the state from out of control program expenses such as those that North Carolina has experienced (e.g. community support). The best opportunity that the MH/DD/SA sectors have for retaining the separate system of services that we have

now is for a few LMEs to successfully operate Medicaid Waivers that are tailored for people served by the MH/DD/SAS system. LMEs must be recognized as successful, effective and efficient waiver operators by the time that the state recognizes the inevitable and absolute need to manage **all** Medicaid services statewide.

- Should the state go forward without a viable b/c Medicaid waiver, MH/DD/SA stakeholders will not be driving the larger Medicaid solution for the MH/DD/SA system, primary and general healthcare will.
- MH/DD/SA services are a tiny percent of overall Medicaid healthcare costs.
- For North Carolina a likely scenario without the b/c waiver may include the need to contract with a major, national Managed Care Organization (MCO) to manage the entire Medicaid benefit. This would leave MH/DD/SA occupying a very minor piece of a benefit plan managed by a remote, large organization with little of no “behavioral health” (MH/DD/SA) expertise; or carved out to a major, national Managed Behavioral Healthcare Organization (MBHO), losing the responsiveness of locally managed waivers run by North Carolina LMEs
- Even if a North Carolina organization (Accountable Health Care Entity such as NCCCN) ends up managing Medicaid financed services, the specialty aspects (non-pharmacological) of MH/DD/SA services will be lost or severely compromised.

Therefore, the real issue in this debate is how, and by whom services and costs for people with intellectual and developmental disabilities are best managed. *The fact that services and related costs for the I/DD population will be managed is a given.* The reality of state and national funding shortfalls now, and projected for the future, makes management of public resources a mandate that cannot be ignored. The management of limited resources is a task best suited for the public sector, since the overall interests of the public must be carefully balanced so as to be in the best interests of all: consumers, families, providers and the taxpayer.

The State has begun to address the challenge of managing the services for people with I/DD through establishing a system of four tiered waivers. Each waiver in the tiered system is a separate waiver, with separate services, enrollment criteria, accountability and cost limits. This may be a good way to manage services and costs in a large decentralized system with over 10,000 waiver recipients. The advantage of this approach is that aggregate costs are limited to the maximum funds per slot in each waiver and an upper limit on the state’s liability can be established by limiting the number of slots funded for each of the tiers. (Medicaid regulations require states to establish a maximum number of people served per year, referred to as slots.) One of the major disadvantages of this approach is that the assurances and regulations for each waiver must be addressed individually, which results in an increased administrative burden for the state at a time when such is increasingly unacceptable. An additional down side of the tiered waiver system is the need to move a person from waiver to waiver in order to meet his or her changing needs if costs are higher than the cap on the tier. Medicaid waivers require states to ensure that the needs of each individual participating in a waiver can be met within the services and cost limitations of the waiver. Each person on the waiting list must be assessed to determine the level of support needed in order to be associated with the appropriate waiver tier. For example, since Tier One (also called the Supports Waiver) does not include residential services, only people that do not need residential supports can be considered for this waiver; and if a person enrolled in Tier One has a change in circumstances or need, the person must be removed from Tier One and moved to another Tier that includes residential supports. If there are no “slots” available in the Comprehensive Waiver, the person must wait until a slot becomes vacant, or new slots are added. Adding slots to these waivers requires the state to submit a waiver amendment to Medicaid.

Our point is not to criticize the tiered waiver system, but to contrast it to the Innovations demonstration waiver. The upper limit for both the PBH Innovations Waiver and the State's Comprehensive Waiver is the same. What is different is *how the services for individuals are managed* below this upper limit. The PBH waiver has a structured system of cost management with upper limits set at the individual consumer level, *all within a single waiver*.

We believe that the role of the public system is to assist people with intellectual and developmental disabilities to live successfully within the community. PBH does not operate a diagnosis condition-driven model for consumers with intellectual and developmental disabilities such as is appropriate for people with Mental Health and Substance Abuse conditions (sometimes called a Medical Model). We employ staff with strong values and backgrounds in I/DD, make strong use of person-centered planning, and advance self-determination. PBH has specific practice guidelines for I/DD services, uses I/DD specific evaluation tools, has I/DD specific authorization criteria and employs other strategies to manage the Innovations waiver as an exemplary program for children and adults with intellectual and developmental disabilities.

We are also concerned about the needs of our providers of I/DD services because they are integral to the success of our waiver. Recently I/DD providers asked us to strengthen DD expertise within our Utilization Management department. As a result, we have hired a highly qualified and very experienced individual as Director for Developmental Disabilities Services within the Utilization Management Department. We are confident that she will provide the leadership and expertise that DD Providers are seeking. Additionally our I/DD providers have had concerns with the current Benchmark Utilization Management criteria for I/DD services. We are currently working with experts in the field of intellectual and development disabilities to design a Resource Allocation Model, a model that is empirically based, and very transparent in how it is applied. The Resource Allocation model for people with I/DD will be based on the Supports Intensity Scale (SIS). This will ensure that each individual's level of need is closely aligned with the cost of services. Using this system along with a Person-Centered Planning approach will ensure that Innovations is well ahead of the curve in advancing personalized, inclusive, community outcomes at a cost that is sustainable. At present, we are working with providers and consumers on an implementation plan for the Resource Allocation system. The Resource Allocation system will help ensure that people get "no more and no less" than what they need and support the evolution of a system is fair and equitable for all participants.

Advantages of the 1915b/c waiver for people with Intellectual and Developmental Disabilities and the I/DD System

The Innovations Waiver is a separate Medicaid waiver for people with intellectual and developmental disabilities—it is a 1915 c waiver just like the State's CAP-MR/DD waiver. It operates under a managed care (1915 b) waiver; formerly called the Cardinal Health Plan (renamed the MH/DD/SA Health Plan). There are specific advantages for consumers and for the I/DD service system at large of operating under a managed care waiver. These are:

1. Advantage: Provider Network Management.

- a. Under a managed care waiver, PBH can establish high quality standards for providers. We have full authority to enroll and de-enroll providers based on their performance.
- b. We can and have limited the number of providers in our network. However, Medicaid regulations require that consumer choice is ensured. We also have consumer-specific

contracts with providers outside our network that address unique needs of individuals that cannot be met by providers within our network.

- c. Medicaid regulations require that an annual capacity study look at the service needs of consumers and the capacity of network providers to meet this need. Additionally, access to services including geo-mapping of consumers and providers is included in this evaluation. Geo-mapping uses the latitude and longitude of consumer residence addresses and provider addresses to develop maps which enable us to evaluate consumer proximity to provider services. Any gaps in service capacity or in access to service locations must be corrected.
- d. While we operate a "closed" provider network, we have over 100 providers of services for individuals with intellectual and developmental disabilities. We are very committed to having adequate consumer choice of providers (and are required to do so), while ensuring that we offer only providers that have proven quality records.
- e. A closed network in a managed care system is also important in ensuring the health of providers by providing the opportunity for each provider to have adequate market share to support the quality infrastructure that is required. However, the survival of any individual provider in a managed care system is determined by the choices of the people served. If consumers "vote with their feet," providers with whom consumers are not satisfied will be eliminated in a closed network.

2. **Advantage: Inclusion of ICF-MR services.**

- a. The I/DD system cannot be managed without including ICF-MR/DD services.
- b. ICF-MR/DD services are an essential part of the array of services for people with intellectual and developmental disabilities. Leaving out ICF-MR/DD services from a waiver would equate to leaving out Psychiatric Hospital Inpatient Services for the Behavioral Health, except that ICF-MR/DD service costs are 4 times the costs of psychiatric inpatient services, and 50% of the PBH service funding for people with intellectual and developmental disabilities.
- c. ICF-MR/DD services must be used strategically to provide the highest level of services in our system--*a level of care that is needed*.
- d. Because of the flexibility that results from operating the Innovations Waiver and the Managed Care Waiver concurrently, we are able to move people out of ICF-MR/DD facilities *without having to wait for vacant Innovations Waiver "slots."* To date, we have successfully transitioned 12 people out of the state's institutions for people with intellectual and developmental disabilities using the flexibility available through the waiver. This is an example of what is meant by "money follows the person."
- e. We can also transition people from a community ICF-MR/DD facility to a home in the community, keeping the consumer with the same provider, as they often desire.

3. **Advantage: Financial Flexibility.**

The ability to use savings to reinvest in services resulted in the addition of *new services* to the PBH managed care system, including:

- a. Respite for children with mental health and substance abuse conditions; and for children and adults with intellectual and developmental disabilities not enrolled in the Innovations waiver or an ICF-MR/DD facility.
- b. Supported Employment for adults with intellectual and developmental disabilities that are not enrolled in the Innovations Waiver or living in an ICF-MR/DD facility.
- c. The flexible use of funding allows us to move consumers out of ICF-MR/DD facilities without having to have a waiver slot.

When these services were implemented, PBH was able to *reduce our waiting list to zero* for people with I/DD services that were waiting for these two services!

Management of Risk is a responsibility that comes with Financial Flexibility. There are provisions within managed care systems that support the management of risk by the operating LME.

1. Rates paid to the LME: Medicaid regulations require that rates paid by states to managed care entities must be adequate (actuarially sound) to cover the costs of services. The state's actuaries must provide a certification to the Centers for Medicare and Medicaid that the rates are adequate.
 2. DMA Contract Requirements: The Division of Medical Assistance contract with PBH requires that PBH maintain a Risk Reserve of 15% of waiver funding for cost over-runs. PBH cannot access the Risk Reserve Funds without the permission of the Secretary of DHHS. Funding from the PBH Risk Reserve has never been used.
 3. Medicaid regulations do not allow the managed care operator (PBH or any LME) to pass any costs on to consumers under any circumstances.
 4. PBH provides reports to the Division of Medical Assistance (DMA) on a regular basis; these reports are reviewed and discussed by PBH financial managers and DMA financial staff.
4. **Advantage: Flexibility of Medicaid capitation payments to the LME.** PBH receives a separate capitation payment for Innovations Waiver participants. Innovations services are budgeted and managed separately from the services in the managed care waiver. State actuaries make adjustments for over- or under-spending across the various payment categories annually. Because Medicaid waiver funding is adjusted annually for inflation, program changes, and utilization of services, there is no incentive to move funds from one disability group to another. Medicaid waiver funding is customized to the needs and utilization patterns of the waiver population. Medicaid regulations require the state to pay the waiver operator funds that are adequate. Additionally, PBH has realized significant savings in mental health and substance abuse services and has had no incentive to use DD funds to pay for services for consumers with Behavioral Health conditions.
5. **Advantage: Efficient and Effective Delivery of Support for People with I/DD that Ensures Access to Appropriate Services.** In the Innovations Waiver, the service planning, service plan development, and monitoring functions are provided through a combination of Care Coordination (not a service but a function available under a Medicaid Managed Care Waiver) and Community Guide, an innovative service included in the Innovations waiver service array.
- a. Community Guide. The Arc NC is a provider of Community Guide, a service that offers community linkage and advocacy for consumers enrolled in the Innovations Waiver. This service serves as an ally and advocate for the individual and guardian. The service also works to integrate the person into existing community activities that are of interest to the individual. We have found that Community Guide staff members are often family members of people with intellectual and developmental disabilities. Family members can bring a level of support and understanding to other families that professionals often cannot provide. We have been very pleased with the dimension that Community Guide has brought to the system of services and supports for people with intellectual and developmental disabilities.
 - b. Targeted Case Management Services. We recognize that the Arc NC is a major provider of case management services under the CAP-MR/DD waiver. PBH is moving the service Targeted Case Management for individuals with I/DD to private agencies in July 2010. This service is available for non-Innovations participants.
 - c. Care Coordination. The role of Care Coordination is to ensure that the individual receives needed assessments, and that the planning process includes identification of the

person's goals in accordance with outcomes such as those defined by the Council on Quality and Leadership; that the meeting includes key stakeholders such as providers and people that are important in the person's life; that assessment information, including the Supports Intensity Scale (SIS), is available to planning participants; and that the meeting is conducted according to the principles of Person Centered Planning. The Care Coordinator is an expert on the Innovations Waiver service array, and is charged with informing the individual and the team about options available to the person under the waiver, for ensuring that the individual has been adequately informed of his or her choices of services and providers, and with putting together a plan that represents the person's choices and the final recommendations of the team. The Care Coordinator is the catalyst of change by ensuring that the person and his/her team considers all possible support options and introducing new ideas as appropriate. The Care Coordinator is also charged with monitoring the health and safety of the individual.

We have found that this blend of Community Guide and Care Coordination is essential in ensuring that people receive appropriate services and that their Person Centered Plan represents the priorities of the person receiving services.

Response to specific areas of concern defined by the Arc NC

Problems in transferring consumers between the Innovations Waiver and CAP-MR/DD. In 2005 when the Innovations waiver started, there was a problem in transferring consumers between waivers. However, this problem was solved by state officials, and transfers frequently occur. To date, 20 people have transferred from the Innovations waiver to the CAP-MR/DD waiver, and 30 people have transferred from CAP-MR/DD to the Innovations waiver.

Limitations in expansion of slots for the Innovations Waiver: We appreciate the significant efforts of the Arc NC in advocating to the General Assembly that PBH be included in funding for expansion slots. Prior to this effort, we had not been included in expansion planning. We understand that Secretary Cansler intends that future expansion funding for waiver slots for the I/DD population is allocated equitably across all LMEs in the state. The appropriation of state match for expansion of the Innovations Waiver is under the jurisdiction of the General Assembly, just like the CAP-MR/DD waiver.

Prohibit Innovations Waiver Expansion: The position statement of the Arc NC questions how the state made the decision to expand the PBH model. It recommends that PBH expansion be prohibited.

There are extensive Federal Regulatory and Accountability requirements that must be met for the operation of any Medicaid waiver. PBH regularly reports over 60 individual performance measures to the state. Since April of 2005, we have been involved in four External Quality Review Assessments by an agency external to the state; two additional evaluations, also by an organization contracted by the state; four state-level evaluations by another state contractor; many plans of improvement; and in February 2010 we obtained full accreditation from the National Council on Quality Assurance (NCQA). The Innovations Waiver contains numerous performance and quality measures that are evaluated by the Centers for Medicare and Medicaid at least each time the waiver is renewed. Additionally, on an annual basis PBH contracts with external organizations to complete a consumer satisfaction survey, a provider satisfaction survey and a stakeholder satisfaction survey. PBH has consistently had strong performance on all of these measures, and has responded to areas where improvement is needed. We would be happy to make any of these evaluation documents available for review.

PBH has achieved both systems and individual consumer outcomes which have been measured and documented by outside entities. Systems outcomes are measures of how the PBH demonstration impacts the community and the people we serve as a whole. Individual outcomes are measures of specific individuals and achievement of goals related to their individual needs and preferences. Of particular interest to I/DD stakeholders should be the PBH performance on the Core Indicators Outcomes Assessment (conducted by HSRI through a contract with the Division of MH/DD/SA). We have attached both Individual and Systems outcomes to this document.

PBH Expansion of Waiver Operations to Other LMEs Should be Prohibited: Because a managed care waiver includes financial risk, LMEs with small populations will be at a great disadvantage if they were to operate an At Risk 1915b/c waiver. A larger population ensures greater financial flexibility and diminishes financial risk of the waiver operator. LMEs are currently considering how they can best serve people in their catchment areas in the MH/DD/SA system of the future. Each entity must evaluate the pros and cons of an endeavor such as a merger and ultimately determine what is in the best interest of those it serves. For example, in our most recent merger with Davidson County, we found that Davidson County officials, the Davidson County LME Board, and the Director of the Davidson County LME were focused only on what was best for the people of Davidson County. Davidson County had no financial or management problems; they were under the population limit but they were not pressured to merge. There was something for everyone involved to lose in a merger, including key management jobs, and county level control of the system. However, Davidson County officials were thinking ahead, looking at the direction the NC MH/DD/SA system was taking and the impact this change would have on services for the people of Davidson County. They ultimately decided merger was the best course of action. Together, we are making this work. The PBH commitment regarding any future expansions/partnerships is that there will be strong preservation of a local presence in communities and any changes for consumers, other than increased quality, will be minimal.

Closing

In closing, with the passage of Federal Healthcare Reform, the system of services for people with MH/DD/SA conditions is on the verge of vast change. There is real potential for better coverage for more people; changes in payment and delivery systems; increased accountability and efficiency; and contemporary, valued outcomes for people with I/DD and their families, outcomes that can bring about better quality of life. These improvements will rely on many of the tools and strategies that PBH has been using in the management of our waivers, tools which are well understood in the healthcare arena, as well as tools developed specifically for, or tailored to the I/DD population. It is of strategic importance for PBH to continue to demonstrate how management tools used by the healthcare system can be appropriately and effectively used or adapted to achieve the best services, supports, and outcomes, outcomes that matter to people with intellectual and developmental disabilities and their families. On the other hand, if the MH/DD/SA system is not prepared to change to meet the requirements of the future, people with needs for MH/DD/SA services stand to lose the real advantages that a system tailored specifically to these populations can provide. Ironically, in opposing the b/c waiver, it is the specialty I/DD system that the Arc NC is trying to preserve. The b/c waiver achieves that end for people with intellectual and developmental disabilities.

Attachment: PBH outcomes