North Carolina Legislative and Rule Analysis of Constraints to the Implementation of Consumer-Directed Supports

Combined Report of Major Findings and Recommendations

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*Note: Adult and Family Support is now incorporated into the Division of Aging and Adult Services

BACKGROUND & INTRODUCTION

The Human Services Research Institute (HSRI) was charged with identifying constraints and barriers in North Carolina to the implementation of consumer-directed supports in statute and regulation pertaining to the Department of Health and Human Services (DHHS), and proposing steps to eliminate such constraints. This analysis focused on a range of potential statutory and regulatory constraints that currently, or may in the future, constrain the development of self-directed services for elders, people with physical disabilities, people with developmental and other cognitive disabilities, individuals with mental illnesses and people who experience substance abuse issues.

In November 2004, HSRI staff and expert consultants delivered the first of three reports, a *Summary of Major Findings and Recommendations*, noting constraints and potential barriers within the General Statutes pertinent to DHHS implementation of self-directed services. The second stage of work focused on constraints to self-determination in DHHS regulations and policies. In August 2005, a second report, *Implementing Consumer-Directed Supports: An Analysis of Constraints in Rule and Recommendations for Change*, was delivered. This report combines findings and recommendations of the earlier two reports into one document.

As part of the overall framework that guided our statute, regulation and policy reviews, HSRI described what is meant by consumer self-direction of publicly funded services. Because Medicaid is such an instrumental funding source for home and community based services, HSRI used the framework put forth by the Centers for Medicare and Medicaid Services (CMS) as necessary for self-directed services under Medicaid funding. It is acknowledged that other funding sources may not build their self-directed programs with all these components. HSRI also embraced the Statement of Principles developed by the North Carolina Consumer Directed Task Force, and updated the principles to encompass elders and their caregivers.

This report[*] combines the prior reports into one document and is organized as follows: Section I explains what is meant by consumer-direction of services and supports; Section II identifies the principles the consultants used by which to conduct the analysis of statute, rule and policy; Section III provides a brief history of self-directed initiatives, both nationally and in North Carolina; Section IV yields a synopsis of lessons learned from the history of self-directed initiatives relevant for further policy making; Section V lays out the principle result across the project's scope; Section VI delineates major findings in statute; Section VII recommendations for addressing the statutory constraints; Section VIII major regulatory and policy findings and recommendations analyzed by component of consumer-directed service.

In crafting that report HSRI staff and consultants reviewed statutes pertinent to DHHS, DHHS regulations, interviewed Division representatives and conducted a literature review of initiatives regarding implementing self-determination and self-directed supports in the United States generally, and North Carolina specifically. A list of statutes and regulations reviewed is found in Appendix B, and documents reviewed in Appendix C. Appendix D contains a detailed analysis of specific sections of the Department's rules and policies that potentially bear on self-direction.

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I. WHAT IS CONSUMER-DIRECTION?

Self-direction, or consumer-direction, is a simple but powerful concept that promises to make traditional supports to people with disabilities, chronic conditions, and elders more flexible, more individually tailored, and ultimately more responsive. It is based on the assumption that because an individual requires support does not mean that he or she has ceded control over basic decisions regarding the time, place, nature, provider and duration of those supports. Self-direction assumes a "retail" approach to the provision of services (e.g., one individual at a time) compared to a "wholesale" (e.g., one size fits all) approach.

The specific application of self-direction will be different depending on the nature of the individual requiring support. One of the first applications of self-direction grew out of a movement in the physical disability community to control the hiring, firing and training of personal care attendants. The call for more control over personal care coincided with the larger independent living movement and rejection of more institutional models of care that circumscribed choice and inclusion.

With respect to behavioral health, the evidence of self-direction can be seen in the growth of consumer operated drop in centers during the 70s and 80s and, more recently in the expansion of peer support models and the use of advance directives that spell out the individual's wishes and preferences in times of crisis. In the case of individuals with substance abuse problems, self-direction might take the form of vouchers that can be used to purchase services from a range of vendors.

In developmental disabilities, self-direction has come to mean the participation of the individual in his or her person centered plan, respect for the individual's wishes and goals, the creation of an individual budget allocation, and varying degrees of control by the individual and/or family over the disbursal of such funds either directly or indirectly. Self-direction in developmental disabilities also entails the ability of the individual to make choices about where to live, what to do during the day and the staff that will provide support.

Among elders, the move to self-direction has also coincided with a move over the past several years to maintain individuals who are aging in their own homes as an alternative to placement in residential or nursing care facilities. Since each individual's situation (including natural supports from family and friends) is influenced by a variety of idiosyncratic factors including the degree of dependence, culture, routines and living situation, home supports likewise need to be geared to the specific needs and strengths of the older individual and his or her support network. The HHS/Robert Wood Johnson Cash and Counseling demonstrations illustrated the positive results when elders and their families were given the ability to control resources and direct funds to supports of their choosing, provided at their convenience.

The operational components of self-direction will also vary in their intensity and applicability depending on the group of individuals served. For instance, many people with physical disabilities do not need a "plan" to govern their services beyond the identification of need and resources. Other individuals may have very little interest in actually managing the day-to-day allocation of resources but instead will be content to chose and train their service provider. Given these assumptions, the following is a list of potential components that may, in varying degrees, be necessary to ensure the viability of self-direction.

- **Individualized plan** -- Because self-direction is inherently a highly individualized approach that revolves around the expressed needs and preferences of each person, it is critical that the process of developing individual supports starts with a formal or informal focus on the participant. While not every individual may need or want a plan if not

required by a funding agency, when a formal process is indicated, the individual should be the focal point, and the active participation of individuals who are close to the person (e.g., family, friends, and other allies) should be solicited. The planning process should focus on the person's expressed preferences on how his/her needs would best be met.

- **Consumer control** -- Central to self-direction is the authority of the individual to select workers who provide supports, supervise them and, when necessary, terminate their services. It also includes the participant's ability to make choices among agencies that provide formal supports.
- **Participant allocation** -- Since each individual has different needs and may make different choices about the array of supports that will meet his or her objectives, it is vital that individuals have an identified budget with which to plan and direct toward specific supports.
- **Supports for self-direction** -- To assist and support the individual to make choices, identify relevant specialized and generic resources and manage services, the system should provide information and direction. Accumulated experience with self-direction around the country points to the importance of providing access to a personal agent, broker, or other individual who can perform this role to the extent desired by the individual.
- **Financial management services** -- The presence of financial management services to carry out "back room" functions such as handling payroll taxes, workers' compensation, social security, and tracking the individual allocations can also enhance the ability of individuals to self-direct. Financial management services can support individuals to be the employers of their support workers and, hence, exercise direct control over hiring, supervising and firing workers.
- **Participant protections** -- Self-direction also poses new challenges to public monitoring systems. Since many self-directed supports will be provided in the individual's home or workplace – and not in a more formal setting – the traditional means of assuring the well-being of more vulnerable individuals may not be operative. As a result, it is important that public entities develop alternative monitoring strategies and other health and safety safeguards that are specifically tailored to individuals who direct their own services (e.g., easy access to criminal background checks). It is vital that these protections be respectful of individual choices.
- **Quality management** -- In order to manage self-directed services and supports at the sub-state as well as the state level, it is important to develop solid strategies to track the achievement of participant goals and personal outcomes.

II. Principles for Provision of Self-Directed Supports in North Carolina

It is important to spell out the expectations and aspirations regarding self-direction against which HSRI examined the current statutory and regulatory framework. This task is aided by the Statement of Principles developed by the North Carolina Consumer Directed Task Force and subsequently revised by the Consumer Directed Work Group and adopted by the North Carolina Long Term Care Cabinet. These principles have been updated for this analysis to also encompass elders and their caregivers.

People with Disabilities and Long Term Illnesses and Elders:

- Have the same needs, hopes, desires and feelings common to all people.
- Are entitled to the full benefits of community membership and citizenship, including all of its rights, privileges, opportunities, and responsibilities.
- Must be afforded the dignity of taking risks.
- Must have access to coordinated services and supports, determined by the individual's unique strengths, needs, and choices.
- Must have the opportunity to direct the planning, selection, implementation, and evaluation for their services and supports.
- Are the primary decision-makers in their lives and must be supported and encouraged to achieve their full potential and be afforded the opportunity to develop personal relationships, learn, work and produce income, worship and be full participants in community life.

Community Service and Support Systems Must Strive To:

- Provide safeguards to ensure personal security and wellbeing and affirm and protect individual legal and human rights.
- Be coordinated and person- and family-centered; developed around the individual's needs and strengths, capabilities, and choices.
- Be fully accessible, culturally responsive and provided in the most integrated community setting appropriate to the individual's needs and desires.
- Support the development of informal and generic community resources that are accessible and readily available, and employ specialized services only when those used by the general public cannot reasonably accommodate the needs of the individual/family.
- Be directed toward the enhancement of quality of life and the achievement of interdependence/independence, contribution, and meaningful participation into the community.
- Support people to be, to the extent possible, the primary decision-makers in their lives by providing them and their families/caregivers with the information and supports necessary to make informed decisions.
- Reflect best practice, be cost-effective, efficient, and achieve outcomes valued by people with disabilities and long term illnesses, elders and their caregivers.
- Be responsible stewards of public dollars, distributing resources to assure that individuals are served equitably and according to need and comply with all accountability requirements governing public funds administered by the system.
- Ensure that consumers or their designated representative meet the responsibilities they agree to assume with regard to directing their own care including making informed and cost-effective decisions regarding services and supports.

In sum, the Consumer Directed Task Force has very clearly identified the hallmarks of self-direction – most importantly that individuals have the opportunity to direct the planning, selection, implementation, management and evaluation for their services and supports; and that the service system ensures that supports are responsive, reliable, safe, and accountable. It was against this backdrop that the following analysis was prepared.

III. Lessons Learned Implementing Consumer-Directed Services

Despite the lack of a strong foundation in statute or regulation to support consumer-directed services, North Carolina, along with other states across the nation, has taken steps to build momentum for self-direction. Some of the initial initiatives that are related to a more individually focused approach to the

provision of services and supports include family support, supported employment and independent living programs. And as Bradley and Agosta wrote, "One can argue that 'self-determination' is less a revolutionary concept and more an evolutionary step that the field was already pushing toward." (RWJF Self-Determination Initiative: Final Impact Report, 2001) North Carolina has initiated self-direction pilot programs and has worked for many years on new waiver service configurations that support individual choice and direction among specific groups of consumers including people with developmental and physical disabilities as well as elders.

The following section briefly summarizes both the national and State specific self-determination and self-directed initiatives.

National Initiatives

The Robert Wood Johnson Foundation Self-Determination Initiative: Final Impact Assessment Report, November 2001

HSRI conducted an evaluation of the Robert Wood Johnson Foundation funded self-determination pilot projects. In 1997 the Foundation sponsored 19 demonstration projects that were broadly representative (e.g., geography, socio-demographics, resources, service configuration, economies, evolution of the public service systems and readiness to support self-determination). The evaluation demonstrated what constitutes critical factors for (or conversely barriers to) success:

- Flexibility in funding streams must accommodate individual budgets and expand the pool of contracted providers;
- Self-determination initiatives are more successful when embedded throughout the system than when treated as a project and leadership is necessary to steer a system beyond piloting; and
- The ability to lead a self-determined life is directly related to the availability of direct support professionals.

Report is available at www.hsri.org

Vulnerable Populations. Determining Personal Care Consumers' Preferences for a Consumer-Directed Cash and Counseling Option: Survey Results from Arkansas, Florida, New Jersey, and New York Elders and Adults with Physical Disabilities, June 2004

This report is a summary of the findings of an evaluation of consumer-driven demonstrations in four states. The project, known as the CCDE - Cash and Counseling Demonstration and Evaluation - was cosponsored by the Robert Wood Johnson Foundation and the US Department of Health and Human Services. It was designed to compare "cost, quality, and satisfaction of Medicaid consumers receiving traditional personal care services with those receiving the cash option." Prior to the Cash & Counseling demonstration project, states, because of federal restrictions, were prohibited from using Medicaid to fund cash payments directly to consumers to purchase their own services. The Cash & Counseling model provided for cash allowances to consumers for personal care, assistive devices and home modifications.

Surveys were conducted with elders (age 65 and older) and adults with developmental disabilities (ages 18-64) in the states of Arkansas, Florida, New Jersey and New York. Findings were used to inform the implementation of a Cash and Counseling program in all of these states but New York. These demonstration projects proved that across the country, adults of all ages as well as across populations are interested in a consumer-directed cash option for personal care and other service supports in lieu of agency-directed services.

Medicaid and Consumer-Direction

In North Carolina as elsewhere, Medicaid is the single-largest source of funding for long-term services and supports for people with disabilities and older persons. As a consequence, expanding opportunities for North Carolinians to take charge of their own services necessarily involves introducing consumer-direction into Medicaid services. Medicaid is a state-federal program. Federal policy and laws establish the fundamental framework and parameters under which states operate their Medicaid programs. For their part, states have considerable latitude in designing Medicaid benefits and service delivery methods within the federal statutory and regulatory framework.

Consumer-directed services are by no means a new concept under Medicaid. Dating back many years, many states (e.g., Massachusetts, Maine, New Mexico) have operated consumer-directed personal assistance services programs through their Medicaid State plans. It has long been established that Medicaid beneficiaries can be positioned to hire, fire, and supervise personal assistants and attendants. Consumer-directed attendant services also have been available in many HCBS waiver programs for several years. For example, Kansas provides for consumer-directed attendant services across all its HCBS waiver target populations (people with developmental disabilities, people with physical disabilities, persons who have experienced a brain injury and elders). The CMS Independence Plus initiative provided states with clearer guidance about how to design and implement HCBS waiver programs that incorporate the more robust approach to consumer-direction direction that includes not only direct participant control over support workers but also control and responsibility for managing and directing an individual budget. A growing number of states (including North Carolina) now operate Independence Plus waiver programs. In addition, many other states have modified their existing HCBS waiver programs to give waiver participants the opportunity to elect to direct and manage the full-array of waiver services. For example, across all its HCBS waiver program target groups, Minnesota now makes Consumer Directed Community Supports available as an alternative to the provider-managed services offered in its waiver programs. While federal Medicaid policy poses some complications, it is clear enough that neither federal policy nor regulations pose significant barriers to implementing full-featured consumer-direction of community-centered Medicaid long-term services.

At the state level, the design of Medicaid benefits and service delivery methods are affected by a variety of factors, including generic state laws and regulations that govern medical practices (e.g., a Nurse Practice Act) and service delivery system structure and organization. As a consequence, Medicaid-funded services are subject to the underlying state policies that hold sway. For example, some states require that the admission of an individual to a nursing facility be recommended by a physician. There is no federal requirement that a physician must recommend the placement.

Self-Determination and Self-Directed Initiatives in North Carolina

Choice, Change, Community: Charting a New Course for Customer–Driven Long-Term Supports for North Carolinians with Developmental Disabilities, 1997

This report was the product of a group assembled by the North Carolina Council on Developmental Disabilities by the Customer Managed Care Leadership Initiative to look at the problem of waiting lists for services. Beginning in 1996 the group met monthly and developed implementation strategies for self-directed services in the state. This workgroup developed core principles, determined a structure for such service delivery, and recommended a series of pilot projects to institute self-determination.

Today's Choice: Tomorrow's Path - An Evaluation of the System for People with Developmental Disabilities in North Carolina, December 2001

Today's Choice looked at several areas of the service delivery system to persons with developmental disabilities in North Carolina, including eligibility determination for services, financing and cost tracking, service and support planning, quality assurance and system oversight, system configuration, Medicaid waiver changes and workforce development. For each of these areas, recommendations for system improvement were made along with a suggested lead agency for each task. This report was prepared for the North Carolina Legislative Oversight Committee on Mental Health, Developmental Disabilities and Substance Abuse System Reform and is available on the HSRI website (www.hsri.org).

Of particular interest to this effort are the areas of service and support planning, which included very specific recommendations regarding financing and cost tracking of services. The report acknowledges the difficulty of any agency to meet the individual demands of each of its clients, but recommends that service coordinator team members concentrate on the expressed preference of people regarding their needs for supports and the agencies that should provide them. The report stresses the importance of clear analysis of not only support requests and preferences, but the capacity and/or hindrances to providing them. Recommendations for Financing and Cost Tracking address not only systematic concerns such as creation of tracking tools for specific funding streams and processes for implementing regulations, but also policy issues such as the removal or addition of requirements for eligibility for funds and the revision of spending caps for specific groups of consumers or services.

Self-Determination Efforts for People with Developmental Disabilities in North Carolina: A Report on Three Years of Observation and Evaluation, June 2003

This report includes findings based on an evaluation by Jim Conroy of Pilot Projects in Self-determination funded by the North Carolina Council on Developmental Disabilities. The evaluation team tested the three elements of the 'theory' of self-determination in the individual lives of the participants: 1) If power shifts (carefully, gradually, responsibly, case-by-case) from paid professionals toward the people and their freely chosen allies, 2) then lives will improve, and 3) costs will be the same or lower than they would be in the traditional professionally dominated approach. The report highly praises the efforts of North Carolina in this area and concludes that the data show, conclusively, that these efforts have been successful in all three components of self-direction.

CMS Systems Change Grants, 2001 and 2002

North Carolina has been developing infrastructure and piloting consumer-directed programs as a result of receiving CMS Systems Change Grants in 2001 and 2002. The Real Choice grant focused on recruitment and retention of direct care workers through development of a career ladder and a direct care workers association, and it also funded four pilot projects to further consumer-directed efforts. Two of the pilot projects developed consumer-directed services under a 1915(c) Medicaid waiver. Another pilot developed a fiscal intermediary construct, and the fourth created a peer supports program for individuals who have mental illness.

The Community-Integrated Personal Assistance Services and Supports (CPASS) grant has been developing and field-testing a toolbox of educational materials regarding consumer-directed supports, and has four pilot projects assessing communities and creating strategies to address barriers. Finally, the CPASS project is funding this analysis of legislation, rules and policies across the Department of Health and Human Services, in order to determine where there might be barriers to implementing consumer-directed supports.

DMHDDSAS Blueprint for Change 2004-2005

The Blueprint includes a specific objective to "Develop best practice for self-directed services." The objective further states: "The Division will develop structures that make it possible for people with disabilities to choose self-directed options for the delivery of services."

Independence Plus Waiver in North Carolina - 2004-2005

In 2002, as part of the President's New Freedom Initiative, the federal Centers for Medicare & Medicaid Services (CMS) launched the Independence Plus initiative to provide states with clear guidance about how individual and family direction of services can be incorporated into Medicaid home and community-based services (HCBS) waivers. Under this initiative, CMS developed waiver application templates that were specifically designed to "promote family or individual independence and choices regarding the selection of long-term care supports and services provided in the home" (www.cms.hhs.org). Through Independence Plus, CMS provided states with a road-map about how to provide for: (a) individual and family control over and responsibility for an individual budget; (b) individual/family leadership in service plan design, including the use of person-centered planning methods; (c) individual/family hands-on direction of service delivery, including the recruitment, hiring, supervision, and firing of workers; and, (d) flexibility in managing the individual budget, including altering the mix of services and supports that the person receives. Independence Plus also provided much clearer guidance about the financial mechanisms that could be used to implement consumer-direction in an HCBS-waiver program and better identified the necessary supports and safeguards that must be available to individuals who direct their own services.

North Carolina seized upon the opportunities afforded by Independence Plus to develop, submit and gain CMS approval for two waivers with self-directed components. The first, an Independence Plus HCBS waiver called CAP–Choice, affords the opportunity for CAP/DA waiver participants in Cabarrus and Duplin Counties to elect to direct their waiver services. CAP-Choice was implemented in January 2005. The second North Carolina HCBS waiver with self-directed components is the Piedmont Innovations program that replaces the CAP/MR-DD waiver in the five-county Piedmont service area. The Innovations waiver provides waiver participants the opportunity to direct an individual budget and exercise a wide-range of direct control over their services. The Innovations waiver was launched in April 2005. Both of these waiver programs embrace the central features of consumer-direction. They put North Carolina on a pathway that leads toward wider-spread adoption of self-direction.

DMHDDSAS is developing a new waiver that embraces participant choice and control over services. The development of this waiver is a collaborative effort among a stakeholders group composed of providers, advocates, family members and people with disabilities that are assisting the Division in concert with the Division of Medical Assistance to design the structure and operational protocols of this new waiver. The development of this waiver will propel North Carolina even farther along toward the wider adoption of self-direction.

Implications from Self-Determination Initiatives

These reports and initiatives demonstrate the quantifiable desire of consumers and families to self-direct both in North Carolina and nationally. North Carolina obviously has a substantial history with self-directed initiatives that affirms the State's interest in offering this service option to DHHS clients. We see concrete lessons from each of these reports and pilots that validate the initiation of broad scale policies that affirm and encourage the implementation of self-direction across the state.

Momentum is building through the consumer-direction pilots in Duplin and Cabarrus counties as part of the CAP Choice waiver, the CAP-MRDD self-directed waiver under development, the Piedmont

waiver which began April 1, 2005, and the Easter Seals UCP Fiscal Intermediary service to support the Cabarrus County pilot.

The next step is to capitalize on the momentum generated by these efforts to develop a policy, regulatory, planning and funding framework that will allow flexibility within traditional models for the option of self-directed services across Divisions and populations -- including those currently not covered by Medicaid waiver initiatives.

IV. Summary of Findings Across Statute, Rule, Regulation and Policies

North Carolina is a state primed to offer its citizens more choice and control over how services are delivered. Pilot projects and initiatives have been present in the State for years, and new initiatives are continuing that momentum. As of this report however, such service flexibility is still primarily a nascent program available inconsistently across Divisions and even within different programs in the same Division. Thus most DHHS clients are not yet knowledgeable of such a service option and therefore are not requesting such options be made available.

As this combined report describes in the following sections, there is very little in statute, regulation or policy that constitutes major constraints to implementing a self-directed service option for DHHS clients. On the other hand, there is not as yet a solid foundation in statute or regulation that specifically affirms, provides the underpinnings for, or speaks to the provision of consumer-directed services. So, rather than having obvious written constraints, the lack of a foundation in statute and regulation for consumer-directed supports serve as constraints through lack of emphasis. This can be a major barrier in implementing new programs. As statute and regulations often run behind developments in service delivery philosophy, North Carolina's situation with respect to a foundation for consumer-directed services is not atypical. However, now is the time to implement a framework that will allow flexibility in service models.

Our recommendations, taken as a whole, suggest that a new set of policies are required to flesh out and define the components of self-directed services outlined above rather than overhauling existing provisions. Obviously there will be transitional costs – moving from current service models into service models that allow for self-direction where clients express interest – but such costs over the long run have been shown to be less than traditional service models. And more important, consumer-directed services have been shown to be much more satisfying to clients and thus worthy of the system change efforts involved.

V. MAJOR STATUTORY FINDINGS REGARDING CONSTRAINTS TO SELF-DIRECTED SERVICES

General Statutory Issues Relevant to all DHHS Divisions

- To date the experience with self-direction has been limited in North Carolina across all of the populations covered by this project. As a consequence, there is a limited understanding of the tenets of self-direction, little in the way of positive examples in practice, and a minimal demand for the availability of self-directed supports;
- While there are no obvious restrictions on self-directed services in the pertinent NC statutes, there are also no provisions that directly address self-direction, define the outlines of self-direction, or affirmatively encourage its application;
- With respect to the Medicaid provisions in the General Statutes, there is no language that would stymie the implementation of self-direction, nor is there any affirmative authorization to seek federal reimbursement for self-directed services;
- The state has a foundation for consumer directed supports as it has been providing services through this mechanism through the Independent Living Program from Vocational Rehabilitation for many years. The state has taken some additional recent important steps toward self-direction through the design of the CAP/DA-Choices waiver and the Piedmont Innovations waiver – both of which, when implemented next year, will provide important operational experience that may serve as a platform for expanded initiatives. It also is encouraging that the Department intends to apply for a Medicaid Independence Plus waiver that will operate side-by-side with the current CAP/MR-DD waiver program;
- Because self-direction anticipates that individuals will in most instances function as the legal employers of their support workers, the state will need to re-examine its workers' compensation laws. Positioning individuals as employers of their workers poses liability issues which can be mitigated if workers' compensation coverage can be obtained. North Carolina's present statute (Workers' Compensation Act contained in Chapter §97) does not appear to be especially well-geared to support self-direction. This topic bears further investigation;
- The lack of affordable housing is an obstacle to home and community services and, thereby, consumer-directed services. Except for the Special Assistance In-Home fund (which is limited to 800 slots), North Carolina does not furnish additional assistance to individuals who want to reside in their own homes and receive services. In contrast, individuals served in adult care homes and mental health group homes are eligible to receive State-County Special Assistance. State-County Special Assistance funding is not portable or designed to follow individuals into their preferred living arrangement.

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- According to the Final Report by The North Carolina Study Commission on Aging, the laws governing guardianship in the State have not been substantively changed since 1977. Since that time there have been numerous changes in the fundamental conceptions of guardianship including reforms that preserve the legal rights, freedom and autonomy of individuals. Although North Carolina law previously allowed limited guardianship the law was not clear. With the enactment of House Bill 1123 during the 2003 session of the General Assembly, the law was changed to expressly authorize the option of limited guardianship to all and to encourage consideration of its use. Rights reserved under limited guardianship align with the tenet of self-direction to make one's decisions to the extent possible, and provide for retaining the right to marry, to vote, to be a witness, to

make a will, the privilege to drive, and the right to contract. Now that reform has been adopted, the state should initiate strong support in this needed reform area that crosses all populations encompassed in this study.

- While the provisions of a state's nurse practice act sometimes pose obstacles to self-direction, there are no provisions in North Carolina's law that raise red flags. §90-171 et seq. (Nurse Practice Act) governs the practice of nursing in North Carolina. §90-171.43 provides for nurse delegation of the performance of activities, and includes provision for delegating care (including to a member of a person's family) under the supervision of a nurse for services which are routine, repetitive, and limited in scope not requiring professional judgment of either a RN or LPN. As supervision is not defined, it may accommodate a variety of oversight methods such as telephone consultation, annual service plan development and review, in person instruction, and caregiver demonstration of competencies. Nurse delegation will be explored further during the next phase of project review.
- There do not appear to be provisions in statute for conducting criminal history checks of direct care workers who are hired individually by a consumer. In contrast, mandatory criminal history record checks are required in statutes §122C-80 for persons offered employment by an area program or by a contract agency of an area program, §131E-265 for employees of nursing homes and home care agencies, and §131D-40 for employees of adult care homes. It is unclear whether §122C-80 applies in the case of individual workers who are directly hired by a participant. In the context of self-direction, persons who hire their own workers should be able to obtain criminal history checks. In addition, performing such checks is a critical safeguard.

Statutory Issues Relevant to Division of Medical Assistance

- Chapter §108A:54-70.5 (Social Services) authorizes the Department of Health and Human Services (DHHS) to establish and operate the state's Medical Assistance (Medicaid) Program. Going forward, the Medicaid program will play an important role in expanding opportunities for individuals to self-direct because Medicaid is the most important purchaser of long-term services and supports for elders and people with disabilities of all types and ages. This part of the statute broadly describes the scope of the state's Medicaid program. It also addresses various elements and operations, including such topics as provider and recipient fraud, estate recovery, transfer of assets, and others. The statute does not specify or enumerate the services that North Carolina's Medicaid program offers nor does it specify the groups of individuals for whom Medicaid services will be provided. Instead, it contains a broad provision that: "The Department may authorize, within appropriations made for this purpose, payments of all or part of the cost of medical and other remedial care for any eligible person when it is essential to the health and welfare of such person that such care be provided, and when the total resources of such person are not sufficient to provide the necessary care." This part of the General Statutes does not contain provisions that are either supportive of or inimical to self-direction of Medicaid services.

  We note that there is considerable policy direction concerning Medicaid services that is incorporated in the Budget Act. The current Budget Act contains a provision that might affect the implementation of self-direction. This provision dictates that Medicaid-enrolled providers must purchase a performance bond in the amount of $100,000. Obviously, such a requirement would be onerous for small provider agencies or

individual consumer-hired workers to meet. However, the provision permits DHHS to waive or limit this requirement based on dollar billings.

Statutory Issues Relevant to Division of Aging and Adult Services

- §143B 180-181.55 offers ample statutory basis for the Division on Aging and Adult Services to exercise leadership, technical assistance and monitoring re: consumer directed services. Though there are restrictions placed on the conduct of elder services by the federal statute, the Division also has substantial discretion and funding. The Division, therefore, could theoretically have a more direct and powerful effect on consumer directed service development. Although the statute provides an initial platform for self-directed services, it does not make specific reference to consumer choice or self-direction in the provision of individualized services. §143B-181.3 contains a Statement of Principles which includes some general elements that could be built upon as an initial platform for self-direction:

  (1) Older people should be able to live as normal a life as possible.
  (2) Older adults should have a choice of life styles which will allow them to remain contributing members of society for as long as possible.
  (3) Preventive and primary health care are necessary to keep older adults active and contributing members of society.
  (5) Transportation to meet daily needs and to make accessible a broad range of services should be provided so that older persons may realize their full potential.
  (9) Options in housing should be made available.

- § 131D-19 focuses on the rights of individuals in adult care homes and asserts principles of autonomy within the facility: *It is the intent of the General Assembly that every resident's civil and religious liberties, including the right to independent personal decisions and knowledge of available choices, shall not be infringed and that the facility shall encourage and assist the resident in the fullest possible exercise of these rights.* § 131D-21 details the specific rights.

- **§** 131E contains a Nursing Home Patients' Bill of Rights covering persons living in nursing homes, adult care homes licensed pursuant to G.S. 131E-102, and nursing homes operated by a hospital which is licensed under Article 5 of Chapter 131E. The statute notes the General Assembly's intent to promote the well-being of persons residing in these facilities beginning with establishing their right to make informed decisions, "...every patient's civil and religious liberties, including the right to independent personal decisions and knowledge of available choices, shall not be infringed and that the facility shall encourage and assist the patient in the fullest possible exercise of these rights".

- §131E-117 sets out a number of particular rights. One considered by advocates and self-advocates to be extremely important -- to present grievances and recommend changes in policies and services, personally or through others without fear of reprisal, restraint, interference, coercion, or discrimination -- is available to those residing in facilities. §131E-124 requires the Department to triage complaints for urgency and to investigate within reasonable time frames set out in the statute. To further strengthen these rights the legislature has given the path of legal remedy for enforcement. §131E-123 provides for the right to pursue a Civil action in order to enforce the rights denoted, and allow for others to institute the Civil action on behalf of a person in the facility. These provisions do not address people receiving home supports or those who are interested in directing their own care.

- §143B-181.15 establishes a Long-Term Care Ombudsman Program in North Carolina to assist residents and providers in the resolution of complaints or concerns, to promote community involvement and volunteerism in long-term care facilities, and to educate the public about the long-term care system. Additionally, the Ombudsman Program serves an important function by its duty to report to the legislature on data related to complaints and conditions, to identify significant problems and recommend solutions. While the Ombudsman Program serves to enhance the quality of life and provides a means to monitor the quality of care for users of long-term care, there is not a parallel program for persons living outside of the statute's defined long-term facilities. §143B-181.16 defines such facilities as nursing homes, intermediate care facilities, and adult care homes.

Statutory Issues Relevant to Division of Mental Health, Developmental Disabilities and Substance Abuse Services

- § 122C-2 (Policy section) contains Olmstead-like language affirming the obligation of the state to provide community based services when such services are appropriate, are unopposed by the affected individuals, and can be reasonably accommodated within existing resources. There is no specific reference to consumer-directed services or consumer choice of services within this general policy construct.
- § 122C-2 defines those services that LME's must make available to all eligible individuals and include (1) screening, assessment and referral; (2) emergency services; (service coordination); and (3) consultation, prevention and education. They are not intended to include or define individualized, community based services that would be provided to "target populations" as defined by the Secretary. While these services and supports might include self-directed options, there is no specific reference to any type of community services or supports, nor to consumer direction, consumer choice, person-centered planning, individualized service planning, etc. Thus there is no statutory policy established that would create an impetus for LMEs or providers to create such services. Nor is there a statutory basis for consumers to expect or demand consumer-directed or individualized community services or supports.
- § 122C-3 (9a) again defines core services, as screening, assessment and triage or prevention, education or consultation. Specific service types to be available on an equitable statewide basis to defined priority target populations are not enumerated in the statute. There is no reference to specific direct services and supports that should be available to consumers. Nor is there a reference to consumer directed services, person centered service planning, etc.
- It is noted that §122C-3(14) defines the term "facility" as "any person at one location whose primary purpose is to provide services for the care, treatment, habilitation, or rehabilitation of the mentally ill, the developmentally disabled, or substance abusers." This definition would seem to encompass individual staff who are directly hired by consumers under a consumer-directed model, and could potentially be confusing in regard to whether individual staff must meet the requirements of facilities or licensable facilities that are further defined in rules. §122C-3(14)(b) defines a licensable facility as one that "provides services for one or more minors or for two or more adults." §122C-22(8) provides for the exemption from licensure for "facilities" that provide "occasional respite" for two or fewer persons. The implications of these provisions for self-directed supports will be addressed in greater detail during the next phase of this project.
- § 122C-3 (7) defines a client advocate, "whose role is to monitor the protection of client rights or advocate on behalf of a specific client in a facility." This definition is outdated

and refers to the "client advocates" who are state employees working in state institutions. In the newer sections of the statute, i.e. Article 1, the term "consumer advocate" is used, which has a broader definition. Given that this definition is confusing, project staff may want to address the issue in the review of rules that follows.

- § 122C-10 – 20 MHDDSA provides for a relatively strong consumer advocacy/consumer rights presence and function at the level of the Secretary of Human Services. All of these sections are subject to appropriation, and there has been no appropriation to date. In the future, implementing these sections could provide a more clear focus and stimulus for consumer directed services and a source of state and local advocacy for such services.
- § 143B-216.65 establishes the North Carolina Traumatic Brain Injury Advisory Council to study the needs of persons with brain injury and their families, and to make recommendations to the Governor and DHHS regarding the planning, development, funding, and implementation of a comprehensive service delivery system. This Council too may assist with promoting and implementing self-directed services.
- § 143B-403.1 creates a statewide protection and advocacy program in accordance with the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. §6000) and the Public Law 99-319 as amended, the Protection and Advocacy for the Mentally Ill Act of 1988. In North Carolina this statewide protection and advocacy program is housed in the Governor's Advocacy Council for Persons with Disabilities (GACPD). GACPD investigates complaints made by, or on behalf of, incompetent persons with developmental or mental disabilities who reside in facilities for the developmentally or mentally disabled who have no legal guardian, and to pursue legal, administrative or other remedies to insure the protection of rights of all developmentally, mentally, physically, emotionally and otherwise disabled persons who are receiving treatment, services or habilitation from any State, local or area program. The GACPD may have a role in promoting and implementing the State's move to providing self-directed services.

Statutory Issues Relevant to Division of Vocational Rehabilitation

- The state vocational rehabilitation statute (GS 143-545.1) calls for individuals with disabilities to be "active participants in their own vocational rehabilitation/independent living programs and shall be involved in making meaningful and informed choices about vocational/independent living goals and objectives and related services they receive" but does not speak to the ability to contract for and manage their own supports.
- Although personal assistance services paid for by Vocational Rehabilitation (VR) through its Independent Living Program are more flexible and consumer-directed than personal assistance services paid for by Medicaid, VR can only provide them to a few people per year because of budget constraints. The Independent Living Program is not really funded to expand services to new individuals unless individuals currently on the program stop receiving those services. If a person has another source of payment (e.g. Medicaid/Medicare), it is always billed first. Due to limited funding, the number of persons accessing VR personal assistance remains small. The VR personal assistance program that is connected to vocational training and employment is time-limited.
- The Client Assistant Program (CAP) was established as a mandatory program by the 1984 Amendments to the Rehabilitation (Rehab) Act of 1973. The Client Assistance Program helps people with disabilities to gain access to needed rehabilitation and other supports. Helping people make informed decisions with choice and realize their choices is a tenet of self-direction. CAP services include assistance in pursuing administrative,

legal and other appropriate remedies to ensure the protection of persons receiving or seeking services under the Rehabilitation Act of 1973. In North Carolina CAP serves applicants, clients, former clients, and those seeking the services of the Division of Vocational Rehabilitation Services, Division of Services for the Blind, and the Independent Living Rehabilitation Services. North Carolina's Vocational Rehabilitation Services statute §143-545.1 through 548 require the state adopt rules as required by the Rehabilitation Act of 1973, thus our review of constraints to self-determination will continue to the next phase of review.

Statutory Issues Relevant to Division of Services for the Deaf and Hard of Hearing & Division of Services for the Blind

- There were no major constraints to self determination in statute governing services to either Division beyond issues noted above in the general statutory issues section.
- § 143B-163 establishes a Consumer and Advocacy Advisory Committee for the Blind responsible for continual study of the entire range of problems and needs of the blind and visually impaired population of North Carolina and to make specific recommendations to the Secretary of Health and Human Services as to how these may be solved or alleviated through legislative action. As the Committee is to examine national trends and programs of other states, as well as programs and priorities in North Carolina, committee members will play an important role in the development of self-directed services for this population.
- § 143B-216.31 establishes the Council for the Deaf and Hard of Hearing to, among other charges, make recommendations to DHHS on improvement to services and to advise on the quality of services. This Council also could play a role in advancing self-direction for persons with deafness and those who are hard of hearing.

Statutory Issues Relevant to Division of Social Services

- There were no significant constraints to self determination in statutes governing services to and protections for children.

Statutory Issues Relevant to Home Care Services

- "Home care services" are defined in Chapter §131E-136(3) as including nursing care as well as "in-home aide services that involve hands-on care to an individual." The statute specifically excludes from the definition of "home care services" (and, hence, licensing): (a) programs operated under the authority of §122C and (b) as noted above, services rendered by "an individual who engages solely in providing his own services to other individuals." The exclusion of individual providers of home care services from licensure likely will facilitate self-direction. The provisions of this statute and its associated regulations will prove to be especially important in the context of promoting self-directed supports for persons with disabilities and elders.
- §131E-256 provides for the establishment of a Health Care Personnel Registry to compile information about workers who have committed abuse and neglect. Workers included in the scope of this registry include employees of adult care homes, home care agencies, and residential agencies (but not services provided outside residential or 24-hour agencies) under 122C. Here again, this statute applies to traditional provider agencies but does not appear to apply to individuals who might be directly employed by a service recipient.

Cross-Population Statutory Issues

- Chapter §97 (Workers' Compensation Act). A major concern in implementing self-direction is that service recipients might be liable when the workers whom they hire are injured on the job. When services are obtained through traditional providers, those providers address this type of liability by purchasing workers compensation insurance. However, acquiring such insurance can be difficult for service recipients. North Carolina's present workers' compensation laws do not appear to be especially well-geared to supporting self-direction. Workers' compensation insurance is only mandatory when an employer employees ten or more "domestic service workers" (the most common classification for personal assistants who provide support in a self-directed model). While it is theoretically possible for individuals to voluntarily purchase workers' compensation insurance for personal assistants, it is reported that such insurance is "non-existent" in North Carolina. North Carolina's Workers' Compensation Act may need to be modified to accommodate self-direction. Going forward, DHHS and the state's Industrial Commission should collaborate to identify potential changes in North Carolina's laws or policies to accommodate self-direction.[†]

VI. Recommendations for Addressing Statutory Issues

1. The general provisions for the Department of Health and Human Services (DHHS) should be amended to include specific intent language regarding and encouraging the development of self-directed supports across all of the populations served by DHHS. The language should include the values and principles associated with self-direction and note the potential of self-direction in an operational framework (e.g., person centered planning, individual budgets, etc.). Proposed language is included in Attachment A.
2. The North Carolina Workers' Compensation Act may need to be modified to accommodate self-direction. Going forward, DHHS and the state's Industrial Commission should collaborate to identify potential changes in North Carolina's laws or policies to accommodate self-direction.
3. As self-direction takes hold in North Carolina, the Legislature should develop uniform state requirements for criminal background checks that encompass the individuals hired through any current or future self-directed initiative. The present requirements revolve around the employment of individuals by traditional provider agencies. They do not speak directly to the employment of workers by service recipients.
4. §143-15.3D (Trust Fund for Mental Health, Developmental Disabilities, and Substance Abuse Services and Bridge Funding Needs) is to be used for start-up funds for services that provide more appropriate and cost effective community treatment alternatives; facilitate compliance with the Olmstead decision; and facilitate reform of the MHDDSAS system. Use of some portion of the funds (if there are any left) to fund pilot programs of consumer-directed services in the MHDDSAS system would seem to be clearly within the scope of this section.
5. The issues surrounding State and County Special Assistance, the differential "spend down" requirements for Medicaid eligibility (e.g., living in your own home versus living

[†] For information concerning this complicated topic (including accommodations that other states have made, please see: Susan A. Flanagan, M.P.H. (2004). **Accessing Workers' Compensation Insurance for Consumer-Employed Personal Assistance Service Workers: Issues, Challenges and Promising Practices**. Washington DC: The Westchester Consulting Group. Available at: http://www.hcbs.org/files/43/2104/060704_WC_Final_Report_Narrative_-Final_Version.pdf.

in an Adult Care Home), as well as the "100% of poverty" eligibility standard should be assessed in the impending institutional bias study.

6. The General Assembly Legislative Study Commission established pursuant to Session Law 2004-161 should ensure that its review takes into consideration the relationship of current guardianship provisions to the exercise of self-direction on the part of individuals who are aging, and who have physical and developmental disabilities. Specifically, the Commission should ensure that other options to support decision-making such as advance directives, designation of health care proxies or powers of attorney, use of independent support or brokerage, fiscal intermediaries, and other similar planning tools are used prior to considering guardianship for individuals who are self-directing their services. Where guardianship is necessary, the state should strongly support the use of limited guardianship.
7. As noted above, client protections within a self-directed system pose challenges to conventional quality assurance approaches. In light of the expected expansion of self-direction and the concomitant pressure to develop less traditional supports and more individualized settings, the fit between conventional licensing and "facility definitions" will become more and more strained. The current statutes that define "facility" – licensable and otherwise – did not anticipate self-direction nor did the current licensing rules. To address the mismatch between more conventional concepts of "facilities" and "programs," the Department should establish an interagency task force to review licensing reforms, to explore the separation of "facility" concerns from program concerns, and statutory/regulation changes.

VII. SUMMARY OF REGULATORY AND POLICY ISSUE RECOMMENDATIONS

HSRI is sensitive to the difficulties of developing and implementing major changes in the current body of regulations governing all the various types of services for people with disabilities or elders under DHHS. This is particularly true in systems that are undergoing massive change such as the DMHDDSAS. Thus, we believe that an overhaul of current law and regulation to permit the waiver of current modes of operation would be tremendously inefficient and would further delay the adoption of this option across DHHS Divisions.

Our recommendations therefore build on the current momentum and experience generated by pilot projects by suggesting a strategy of enhanced leadership on self-directed services and providing for development of a parallel system of rules and procedures that provide for the person to choose self-directed supports.

Our review of North Carolina's Medicaid administrative regulations reveals that the regulations concerning relevant Medicaid benefits (e.g., personal care services) are quite brief. They contain only a few provisions that might warrant examination as North Carolina moves forward in amplifying opportunities for consumer-direction. In general, the State's detailed requirements concerning the provision of Medicaid services are contained in policy issuances and program manuals promulgated principally by the Division of Medical Assistance (DMA) or by a program division (e.g., DMHDDSAS) in collaboration with DMA (as has been the case with the CAP/MR-DD HCBS waiver program). It is within the program manuals and other policy issuances where the requirements that govern home and community Medicaid benefits are lodged.

North Carolina has taken significant steps down the pathway of offering opportunities for consumer-direction in Medicaid-funded long-term services and supports. The CAP -Choice and the Piedmont Innovations HCBS waiver programs demonstrate the feasibility of North Carolina's

designing and implementing consumer-directed Medicaid benefits. The planned implementation of the DMHDDSAS Independence Plus supports waiver will be another important step.

The following recommendations are offered with the caveat that adoption of one or more consumer-directed support model options comparable with other types of support options in DHHS will require upfront investments and reallocation of resources. Along with the need for explicit support for consumer-direction in law and regulation, effort is required to rework rate structures, enhance individualized assessment and budgeting, train all stakeholders on the benefits and risks of consumer-directed services, as well as how to manage this type of support with sufficient safeguards. Nevertheless such investment has been proven cost-effective and, equally as important, more satisfactory to service recipients and their families.

The easier piece of this systems change is the adoption of explicit consumer-directed rules and regulations. What is more difficult is the realignment of philosophy. We offer the following recommendations as means to begin the transformation:

1. We recommend that the Department have a mechanism for coordinating self-directed initiatives, following the national trends in self-directed supports, setting a self-directed policy agenda and evaluating self-directed programs as they are implemented. This could happen through designation of one or more staff positions in the Department or in divisions, or through a coordinated body of staff from Divisions with a specifically designated leader.
2. We recommend that the Department continue introducing and implementing smaller scale or demonstration-type programs of self-directed services, within a context of comprehensive and intentional movement towards increasing options for consumer-directed services models across the Department. It is important to think of these initiatives as having the express purpose of generating sufficient information to develop future policy for a Department-wide effort which will inform all parts of the agency.
3. As was stated in our previous legislative report, we recommend that North Carolina draft legislation that will give statutory authority such as Kentucky's Self-Determination Act to enact a new free-standing set of regulations governing all components of self-direction for consumers under the jurisdiction of DHHS. North Carolina's services are, like most states, divided up into the usual types of funding silos. Each of these silos creates its own body of rules and regulations for the conduct of roughly comparable services. Rather than pursing this same duplicative process regarding self-direction, it is recommended the Department adopt common, baseline-policies, especially in the realm of basic personal assistance, and in-home supports in order to avoid creating unnecessary and potentially contradictory rules.

   Alternately, each Division could promulgate its own rules and regulations for self-directed supports. The development of separate sets of rules could be coordinated through the mechanism described in number 1, to create some consistency across the Department. These new regulations would operate in parallel with but would not supersede other regulations of the Department, and would address topics including:

   - Definitions specifically related to the components of self directed service models (e.g., employer of record; individual budget; personal representative, etc.)
   - Person-centered plans and individual budgets
   - Agreements to participate and methods for termination and assuring continuity of services

- Specification of the services currently defined in other DHHS regulations and/or the Medicaid Plan and Waivers that may be incorporated in a self-direction plan and budget
- Specifications for emergency back-up plans
- Requirements for financial management entities
- Standards and requirements for individual providers/personnel
- Responsibilities of case managers, person centered planning teams, LMEs, etc. in self-directed service model
- Incident reporting and investigation procedures
- Quality management activities such as tracking and trending performance indicators related to self direction.

4. North Carolina should consider its opportunities to build on and amplify the availability of consumer-direction opportunities throughout Medicaid-funded long-term community services and supports. This could entail the redesign of PCS/PCS Plus and creating opportunities for consumer-direction program wide in CAP/DA and CAP/C (and any future waiver programs that NC might operate). With respect to PCS/PCS Plus, the main task is benefit redesign rather than regulatory revisions; although some revision may be appropriate in order to establish basic policies governing consumer-employed workers and necessary nurse involvement when such workers perform health-related tasks.
5. With respect to CAP/DA, clearly NC can extend CAP-Choice to additional counties. An alternate strategy may prove to be revising CAP/DA itself to include a consumer-directed option. CMS has revised the HCBS waiver application so that states may include a consumer-directed option in an existing waiver program and obtain a waiver of state-wideness in order to phase in the operation of consumer-direction. Potentially, this means that states can avoid having to operate distinct "provider-managed" and "consumer-directed" waiver programs.
6. Much the same consideration arises with respect to CAP/MR-DD. The new self-directed supports waiver is an excellent step in creating the opportunity for consumer-direction on a statewide basis for people with developmental disabilities. This will set the stage for considering in the future whether CAP/MR-DD itself could or should be redesigned to also include consumer-direction opportunities.

VIII. Major Regulatory Findings and Recommendations by Component of Self-Directed Supports

The regulatory-based findings and recommendations are advanced as a practical analysis that maximizes the facilitation of person-centered and self-directed principles based on the CMS framework for self-directed services, and reflects a pragmatic understanding of what is likely to work and be acceptable to a wide swath of stakeholders.

Below are general findings and recommendations presented by elements of consumer-direction that cut across all DHHS divisions. Division and rule specific analysis and recommendations are located in Appendix C.

Individualized and Participant-Centered Service Plan

An individualized and participant-centered service plan is an important element of self-direction since it is the basis for assessing the individual's requirements for support, the resources that will be required, and the budget that will be allocated. Division representatives we spoke with for this analysis reported that many individual plans are still built around a more traditional service menu. Some Divisions lack basic policies and procedures delineating the service planning process.

The Division of Vocational Rehabilitation's Independent Living (IL) and Vocational Rehabilitation (VR) programs have Individualized Plan templates. Consumer participation in planning has been a requirement for the VR program since 1973. The plans are not menu-driven templates but rather provide blank space for individualized choices. The VR plan may be developed either with or without assistance from a vocational rehabilitation counselor. Regardless of what the person chooses, other resources such as the agency guidelines and information on assistance are provided. Consumers must sign the plan verifying that they have made informed choices regarding the specifics of their plan. The Individualized Plan for Independent Living form includes a place for consumers to sign to waive their right to develop their plan. Division staff representatives note that since an individualized plan is not required by federal law for the Independent Living program, the Division does not make participating in the process a requirement. From the Independent Living conceptual framework, being required to participate in a formal planning process may be seen as detracting from independence and authority. While formal participation in a planning process may not be as big a priority for individuals with physical disabilities, there needs to be assurance that when a person waives the right to participate in planning, this is viewed and implemented within the context of promoting consumer direction. Regardless of the formal or informal methods for planning, the individual should remain in the driver's seat for decision making around needs, preferences and goals.

The Division of Services for the Blind has policies regarding service planning for clients of its In-Home Aide program. There is an individual needs assessment conducted in the person's home that addresses psycho-social, environmental, economic, physical health, and instrumental activities of daily living. The policy, however, does not speak to the person's role in the service planning process or whether the person's goals or preferences are to be considered and addressed and this procedure only takes place once, at the beginning of service planning.

MHDDSAS has very recently issued policy guidance on person centered planning (*Communication Bulletin #34, March 21, 2005)*. While not a regulation, the principles and practices of person centered planning, as espoused in the policy memo, do provide a context for self-direction if other regulatory and financing elements are in place. The Bulletin sets guidelines for implementation of the person centered planning initiative outlined in *The State Plan: A Blueprint for Change*.

To summarize, there are some good contexts for person-centered planning within individual Divisions; however, overall the regulations in the Department of Health and Human Services could be further expanded in regard to person-centered planning. In many cases current service planning processes do not provide an adequate description of what the service planning should entail including whether the client is involved, and to what extent the plan is person centered.

Individualized Service Planning Recommendation: Service planning regulations across Divisions will need to be amended or superseded to incorporate appropriate assessment of client interest and needs for support to self-direct. Assessment and service planning policies and instruments need to incorporate self-direction for all of the populations covered by this study. This is the only

way people interested in self-direction will be identified and supported by the larger systems of care.

With respect to individual assessment – a crucial component of an individualized plan – the application of the Supports Intensity Scale for people with developmental disabilities in the Piedmont area should be closely followed to determine whether it has applicability for self-direction statewide and potentially for other populations.

Consumer Control

Consumer control pertains to the individual's authority to choose his or her own providers of care, as well as to supervise and fire providers, including those providers who are agency-based and those who are not affiliated with agencies. Self-directed practices can make it easier for people to find needed support because the inherent flexibility may open labor resources that were previously untapped. In some states, contracting policies proved to be barriers to expanding the types and quantities of available providers. Self-directed services require agile procurement systems to accommodate the purchase of services and supports from a wider number of sources than typically is the case in specialized service systems. One of the findings of the Robert Wood Johnson study was that those states with tightly controlled RFP processes found it difficult to accommodate individual needs for services not currently part of the "contractor" pool.

However within DHHS there are few programs that allow for clients to hire and fire staff, and fewer still that allow individuals to hire relatives as caregivers. Vocational Rehabilitation's Independent Living program (Personal Assistance), and the Division of Services for the Blind's In-Home Aide Service both provide for clients to hire and fire support staff, within particular programs. Within the Services for the Blind In Home Management Services program, clients are prohibited from employing as aides relatives that are unemployed. Only relatives that give up employment in order to perform the service qualify and may only be reimbursed for five hours of service per week at minimum wage or the county prevailing wage rate.

The Division of Aging and Adult Services is now considering how to offer more self-directed services with elders. This Division's approach is to leave the traditional service system in place and develop the option of self-directed supports as a parallel set of options. The Division is in the initial phase of a self-direction initiative which contains provision for clients to hire and fire personal attendants.

In the mental health and substance abuse system, the primary means of delivering services is through a community support or community support team service. When a paraprofessional staff provides community support or is a member of the community support team, that staff is tied to agency hiring practices and professional level supervision. While the objective of the community support approach is to foster choice, recovery, independence, etc., and this is supportive of self-directed services, there is not an infrastructure whereby consumers can hire staff through a self-directed model for support in daily activities. Self-directed models in mental health are just recently being discussed at the national level, and while there are some pilot programs in some states, it is not clear nationally how self directed supports will link into the evidence-based practices in mental health. As more discussion takes place nationally, it may become clearer how North Carolina can shape its mental health programs to have more self-directed options.

With respect to Medicaid, there are many linkages between the requirements that govern Medicaid benefits and other generic state laws and regulations in these manuals (and the North Carolina Medicaid state plan and the state's approved HCBS waivers). For example, North

Carolina offers a limited Medicaid state plan personal care benefit (PCS) which provides for up to 60 hours of personal care per month, and PCS Plus where an additional 20 hours of services may be furnished. In the CAP/DA and CAP/Children HCBS waiver programs, participants may receive additional in-home aide services that complement the personal care benefit. The providers of PCS, PCS Plus and HCBS waiver in-home aide services are limited to agencies licensed by the DHHS Division of Facility Services under the Chapter 13 Home Care Licensing rules that essentially provide for the licensing of home health agencies. Because in-home aides must be the employees of licensed Home Care agencies, individuals and families do not have the opportunity to be the direct employers of their support workers.

There are additional obstacles posed by current requirements to consumer-direction of services. For example, in CAP/DA case managers are responsible for service coordination but there is not provision for individuals to directly manage their services (with or without assistance). Individuals do not have the flexibility to rearrange their services in their service plans. CAP/DA participants do not have a budget that they can manage. North Carolina's policies limit the providers of CAP/DA respite to in-home workers who are employed by Home Care agencies. There is no provision for CAP/DA participants to directly manage their services.

Related to consumer control is a parallel matter for consideration -- the support needs of direct care workers. A consumer-directed service option would presumably also provide for on-going support to direct care workers, support such as fair working conditions, health insurance, periodic checks on their satisfaction and needs, provision of means to resolve grievances, and sufficient training to competently provide care and support to DHHS clients.

Consumer Control Recommendation: In order to introduce consumer directed services into CAP/DA or CAP/C, the programs will need to be restructured to permit as a voluntary option individuals and families to directly employ and supervise aides who are not the employees of licensed Home Care agencies. CAP-Choice may provide a framework for modifying CAP/DA and incorporating self-directed principles into CAP/C.

We suggest that there should be options so that individuals supported by DHHS could choose self-directed services and thereby hire, fire and supervise support staff from both agency-based and independent labor pools. Such authority can be secured by a separate set of rules for self-directed services and in some cases, restructuring service definitions and delivery systems to accommodate the ability to hire staff through self-directed models.

In addition, program managers may want to examine whether sufficient mechanisms are in place to ensure that there are competent direct care professionals available to be providers of care to self-directing consumers.

Participant Allocation

In addition to choice of providers, individuals who chose to self-direct also need to understand the magnitude of the resources that are available to support their choice. Whether or not the individual chooses to direct the resources or chooses to use an agency to manage the budget, understanding the basic allocation allows the individual to make cost effective decisions.

Individually tailored budgets entail the ability to move money around within a budget, choose services that are not traditional, and purchase services and supplies from vendors without having to go through a home health agency or a state procurement process. Currently barriers exist in the state Medicaid plan with respect to requirements for securing supplies – an individual must go

through a home health agency, or a Local Management Entity (LME) for CAP-MRDD funding, to get supplies. Additionally, State purchasing and procurement policies require the DVRS to follow state procurement processes for client equipment and supplies over a certain dollar amount.

There are still very few pieces of the North Carolina service infrastructure that would support individually tailored budgets. Once the waivers noted above are implemented, there will be individuals in the state with individual budgets and a methodology should emerge to support the design of such individual allocations. However, outside of these opportunities, there are no provisions for sharing budget decision making with Department clients. Not surprisingly, we found no regulatory support for persons to be informed of or manage their individual budget allocations

Participant Allocation Recommendation: In order to take the next steps to self-direction, a cost methodology or methodologies will need to be developed that assists in developing service rates by component parts that can be aggregated on an individual basis. This process can begin by using historic rates for comprehensive services analyzing what the cost components are. Ideally, budgets would be built on scores derived from valid and reliable instruments. The Department already has started work in this area in conjunction with the development of the Independence Plus waiver program for people with developmental disabilities, including examining the use of the Supports Intensity Scale (SIS) as a possible underlying instrument upon which to base individual resource allocations upon which to build budgets.

Further, regardless of the type of individuals who will be using individual budgets, there will be a need for training and support to ensure that people are prepared to manage their budgets.

Supports for Consumer-Direction

While some individuals, such as some individuals currently receiving services as part of the Independent Living program in Vocational Rehabilitation, are very capable of managing all the details of their supports, many people served by DHHS will need assistance and support to gain experience and skill with this mode of service delivery. Experience around the country has proved that many individuals who choose to self direct need a variety of supports to successfully manage supports. Such assistance includes help with recruiting, training and maintaining staff and can be accomplished in a variety of ways including via a personal agent, or broker, peer support, technical assistance, and written materials, etc. A key element of such support is that it be provided by individuals or agencies that are independent from the pool of providers.

In the mental health services and substance abuse system in North Carolina, the community support model combines supports coordination with direct services such as skill training. Thus supports coordination and person centered planning processes are not independent of the paraprofessional level services. As mentioned in the section above on Consumer Control, North Carolina will want to enter the discussion nationally as to how self-directed supports are best operationalized in mental health.

With respect to services to people with developmental disabilities, a supports coordination function in addition to conventional care coordination/case management for individuals who chose to self direct would be highly desirable. The HSRI study of the RWJ self-determination pilots found that providing the role of the supports broker is qualitatively different that conventional case management and calls on somewhat different competencies. Further, given the

somewhat strict requirements surrounding targeted case management, it may be very difficult to satisfactorily integrate supports broker "like" functions.

Regardless of whether DHHS chooses independent support brokers and/or expanded support through traditional case management, most Divisions within DHHS lack infrastructure in rule to support assuring people who chose to self-direct that they will be afforded aid in learning to manage their own services and supports. Where training is addressed in rule, the focus is on training staff in the provision of care and agency policies and procedures than in training the consumer to manage their services.

In the Division of Vocational Rehabilitation Services (DVRS), where self-directed services are in place, those services are restricted to individuals considered 'capable' of independently managing the employee-employer relationship. DVRS offers training to those individuals receiving personal care services, and the array of training topics covers skills relevant to self-directing one's care. For example identifying one's care needs, developing management skills, interviewing techniques, and hiring and firing are some of the training areas available.

As part of the North Carolina CPASS grant, several materials are being prepared as part of a 'tool kit' to assist families and individuals served by the Department who choose to manage their services and supports. The field test of these materials has begun. The tool kit will include PowerPoint presentations, a manual that can be used by consumers/families or by professionals/providers if they are implementing consumer directed supports, and a brochure, and at least one or more videos.

Supports for Self-Direction Recommendation: The Division of Vocational Rehabilitation is in the middle of evaluating its Independent Living Program. We recommend that the review include current policy that limits eligibility for consumer directed personal assistance services to those that are capable of handling the full spectrum of the employer/employee relationship to determine whether this should remain the focus of this program, and consider whether offering some fiscal intermediary-type supports to other individuals deemed less able to manage is something that could be considered.

Support and training for those clients who indicate a preference to mange their own supports needs to be provided across the Department. Further, the development of materials for all of those groups interested in self-direction should include specific information on how to recruit staff, how to train staff, how to supervise and when necessary, fire staff; liability and tax issues, and other "nuts and bolts" issues that are relevant to anyone interested in self-direction.

As well, Divisions in the Department should further review current infrastructures and service delivery systems to assure a staffing mechanism for supporting individuals who need assistance with directing their own services.

Financial Management Services

When people choose self-directed services, they usually perceive this option to mean being an employer, with the responsibility to hire, manage, and fire staff, and managing funds through an individual budget. The legal responsibilities that go along with hiring and firing staff enjoin the self-directing individual to provide for payment of payroll taxes, worker's compensation, social security deductions, and tracking funds. This level of detail is difficult to manage. Thus the development and accessibility to financial management services to carry out these functions enables the majority of persons to delegate these tasks and thus participate in self-directed services.

As mentioned in the section above, the DVRS policy limits eligibility for consumer-directed personal assistance services to those that are capable, independently, of handling the full spectrum of the employer-employee relationship. A question arises as to whether other individuals who, with varying degrees of support, would choose to self-direct, are able to get those services elsewhere.

The Division of Aging and Adult Services tends not to have the same potential constraints in rule as other DHHS Divisions. However, with respect to fiscal agent services, a potential barrier exists if the fiscal agent is designed to be the employer of record. Then home care agency licensure rules come into play and the question of whom is the employer. While a waiver of current licensure rule would address this, the Division is moving forward with developing a parallel rule set specifically for self-directed services, and such rules could readily resolve the barrier.

As part of the Real Choices Systems Change grant awarded to North Carolina, a fiscal intermediary was established to develop the capacity to provide back up functions such as those described above. The mechanism is managed by the newly merged Easter Seal/United Cerebral Palsy organization of North Carolina. The Arc and other agencies in the state have also been providing "agency of choice" related services. The implementation of CAP/Choice and the Piedmont Innovations waiver will serve as the foundation for North Carolina's establishing a broader fiscal intermediary infrastructure.

Financial Management Services Recommendation: The presence of fiscal intermediary supports is a necessary component to facilitate clients of DHHS to consider self-direction of services. Without this component in place, many people who would otherwise choose self-direction will forego the option due to feeling intimidated by the financial and legal responsibilities.

DMHDDSAS has been allocating funds from the Mental Health Trust Fund for community service capacity building. A total of $21.9 million has been allocated for these purposes in FY 2005. These MH Trust Funds are very flexible, and could be used at the discretion of the Division to create service capacity and administrative infrastructure, such as fiscal management services related to self-directed services. As the system continues to move forward with restructuring its service delivery system, it could consider segmenting some of the trust funds for this purpose over time.

Presumably, if fiscal intermediaries are included as a service under the new self-directed CAP-MRDD waiver, specific provider enrollment requirements and qualifications will be developed to regulate this type of support. The concern is that absent new qualifications and provider enrollment requirements, the current licensing requirements would pertain and would require organizational requirements that are not consistent with the functions of an intermediary. Regulations may need to be waived pending the development of new service definitions.

Participant Protections

Self-direction poses new challenges to public monitoring systems because some of the traditional service locations and supervisory safeguards protecting people from abuse, neglect or exploitation are not necessarily operative when an individual chooses to self-direct. When an individual hires a person directly, some of the built in oversight of agency provided supports is missing. A process for incident reporting and investigations, and complaints and grievances for people who manage their supports has not as yet been developed. While constructing systems to address the risks inherent in self-directed services, states typically address monitoring of service delivery and the individual's risk of being victimized. Less commonly considered are the due process

protections that should be afforded the individual with a disability, such as the right to refuse an investigation and to direct the degree and manner of any corrective interventions.

At the first level of consideration is the fitness of persons to be employed as caregivers. When selecting the consumer-directed option, the Department will need to ensure that there is a process for the individual to make an informed choice of providers, with informed choice including timely criminal background checks of putative providers. A number of states have forged policies and procedures regarding background checks for self-directed services. Across most DHHS Divisions, the primary method for ensuring that individuals have not been involved in crime is self-disclosure by the staff, e.g., signing a statement that they have no criminal background. Interestingly, in the North Carolina Medicaid State plan for personal care, licensed Home Care agencies are required to complete background checks on all employees. However, there is no reference to them in the Home Care agency rules. The Board of Nursing Licensing Rules applicable to the Division of Aging and Adult Services, do stipulate that applicants for initial nursing licensure in North Carolina must have a criminal background check. But this does not apply to renewals for nursing licensure. Nor does it apply to non-licensed support staff.

Obviously not all issues that grow out of background checks rise to the level of disqualification (e.g., depending on the nature of the offense and the number of years that have elapsed). Public policy needs to take the individual's wishes into consideration while at the same time ensuring that public funds are not used to support potentially exploitative staff.

Along with safeguards when hiring non-agency directed staff is the issue of medication administration. Medication requirements – specifically for consumers who may need prompting or assistance to self-administer medications – can be a barrier to self-directed services. Although not specifically noted, DMHDDSAS regulations that apply to passing medications seem to apply to 24 hour facilities, not to consumers living at home and self-directing services. However, without clarification the requirements might function as a barrier to self-direction for consumers needing assistance with medications.

Presumably the need to address medication administration applies too to the Division of Aging and Adult Services where with respect to elders, nurse delegation rules may create barriers for delegating medication administration to persons hired by the consumer. With regard to medication and elders, two issues arise. One is whether an activity is a nursing care activity or a patient care activity. Nursing care activities are defined as activities related to health care that may be delegated by nurses to unlicensed personnel. Patient care activities are activities performed by unlicensed personnel when health care needs are incidental to the personal care required. The other issue is who the employer of record is. Boards of Nursing rules are applicable to licensed nurses and even unlicensed personnel with regard to patient care activities. But in cases where health are needs are incidental to the personal care needs of the individual, and where the individual is the employer of record, the rules do not present a barrier to self-direction.

Another important protection is in the area of emergency back up plans. When supports are not provided by agencies, individuals will need to construct back up plans, both for emergencies and routine care.

Participant Protections Recommendation: Policies and procedures for monitoring individuals will need to be reviewed to assure that they apply to individuals who self-direct, in order to assure their health and welfare.

Criminal Background Checks - The Department might consider reviewing its rules to clarify when and how criminal background checks are conducted on any putative personal care staff.

Medication Administration – It is important for individuals taking prescribed medications to be assessed regarding their capacity to manage purchasing, taking medications as prescribed and reporting benefits and side effects. Such an assessment including the level of support needed could be covered in the individual's service plan. Staff providing medication prompting or other supports under the supervision of a self-directing consumer may need additional training in medication administration, handling of medications, and reporting medication errors.

Incident Management - Within all Divisions, incident management regulations or policies and procedures governing self-directed services will need to be reviewed to assure they address monitoring, reporting, investigation, and grievance review of individuals who are self-directing.

Quality Management

The development of quality management (QM) strategies to guide oversight of consumer-direction is still somewhat embryonic. The Piedmont waiver, which was implemented on April 1st, will provide some experience regarding the oversight mechanisms that should be in place as will the implementation of the CAP-Choice pilot. Currently, however, there is nothing in current regulations that speaks directly to quality assurance and quality improvement for people who manage their own supports.

The quality management function of monitoring the person's services and supports and assuring client health and welfare needs to be viewed in terms of persons directing their own supports. This type of oversight is greatly facilitated by the aggregation of key data elements from such quality assurance mechanisms as incident management, abuse neglect investigations, grievances and complaints, consumer and family surveys, and so forth. Maintaining contact with self-direction through key performance indicators and tracking will be critical.

Although many individuals will be fully able to manage supervision and reporting of poor or inadequate care, the fact that many will rely on friends and family to provide paid support places the individual at heightened risk for non disclosure of poor care or exploitation, or even with asserting preferences for care delivery. The individual's service plan is the basic level of assessment of the need for supports to enable an individual to render sufficient staff supervision, and such assessment should address the individual's development of supervisory skills, areas of potential risk and harm, and steps for appropriate intervention where warranted.

Under current DMHDDSAS regulations, paid caregivers must be supervised by a qualified professional or paraprofessional. Because a philosophical and operational aspect of self-direction is in the individual's ability to be the primary supervisor of her own staff, these regulations will need to be reviewed as the service delivery system changes and becomes more educated about a self-directed mode of services. In the Division for Services for the Blind's In Home Management program there is provision for a social worker to support the staff and the consumer via periodic home visits while the aide is present working with the consumer, as well as individual/group conferences to address issues, and telephone contact. These procedures are clear that the person hires the worker and is supervised by the consumer.

With respect to the Division of Aging and Adult Services, supervision for services to elders may need clarification as nurse delegation regulations provide for nurses to supervise and to delegate selected activities. The Board of Nursing is the determining authority on those nursing care activities which may be delegated to unlicensed personnel, and thus either waivers of these

regulations or new rules for self-directed services will need to address transfer/shared responsibility for supervision. With respect to the Divisions of Vocational Rehabilitation and Services to the Deaf and Hard of Hearing, there is no provision or requirement for supervision; new rules for self-directed services could provide that the person is the supervisor and, where needed, for supports to assist the individual with supervision.

Within DMHDDSAS, quality management responsibility is based in the local management entity (LME) and is governed by monitoring requirements for facilities and services. In general, these provisions assume a facility/agency-based provider system -- individual practitioners are included only if they are licensed or certified to practice in NC. There are no provisions that would include intermediaries or direct service staff employed by a consumer or intermediary. A separate set of rules pertaining to self-directed services could be used to clarify the role of the LME in quality management for self-directed services.

Another aspect of quality management is the solicitation of customer feedback. The strength of this type of QM process is that individuals who receive services themselves report on their quality of life. Several Divisions solicit customer feedback. The DMHDDSAS has been involved with the National Core Indicators (NCI) Consumer Survey[‡] collecting consumer satisfaction and outcome information on persons with developmental disabilities since 2000. The NCI Consumer Survey focuses on outcomes in people's lives including outcomes associated with self-determination such as the extent to which individuals are supported to make choices and direct their supports. Indeed North Carolina has even gone beyond the NCI core survey and expanded it to address additional health care issues. Table 1 below demonstrates the results of the NCI consumer survey for 2003-2004.

Table 1 Features of Self-Direction Present for Individuals with Developmental Disabilities

	Fiscal Intermediary	Individualized Service Plan	Individual Budget
% No	86.2%	9.7%	44.1%
% Yes	4.5%	88.8%	51.3%
% Don't know	9.2%	1.5%	4.6%
Total N	444	534	522

Source: National Core Indicators Phase VI Final Report 2003-2004, published January 2005.

Other DHHS Divisions also incorporate customer feedback into their QM systems. The Division for the Blind conducts customer feedback and satisfaction surveys every few years. The Division's survey is brief, in large print and covers whether the person is pleased with their services and whether they received the services they wanted. According to Division staff, the primary feedback they receive is that people need more financial support and transportation assistance – neither of which the Division is equipped to provide. The Division for the Deaf and Hard of Hearing also solicits customer satisfaction feedback. That feedback form focuses on the timeliness of service delivery and the helpfulness of staff . However at the time of this report that data is not yet being compiled for service system improvements.

The Division of Aging and Adult Services (Aging branch) is considering several surveys to cover individuals participating in a self-directed services pilot commencing April 1st – surveys of client satisfaction, direct care workers, and a case manager report on health and safety. This Division already utilizes a client satisfaction survey and a case management monitoring tool in its traditional services.

[‡] The National Core Indicators is a collaboration among participating NASDDDS member state agencies and HSRI. Through the collaboration, participating states benchmark service system performance, and jointly assess and improve performance.

Both the general Vocational Rehabilitation program and the Independent Living Program conduct independent annual consumer satisfaction surveys and are strategically focused on furthering consumer feedback systems. Several initiatives are underway to include consumer feedback on service quality outcome and process measures beyond satisfaction.

Quality Management Recommendations:

Individuals Self-Directing Services Staff Supervision – DHHS will need to waive current rules or craft overriding rules for self-direction within some Divisions to provide for individuals who choose self-direction to supervise staff, with assistance where warranted.

Customer Feedback - As DHHS expands consumer-directed services, all Divisions should conduct customer feedback on satisfaction and outcomes. Questions pertaining to satisfaction and outcomes regarding the various components of self-directed services, (e.g., service planning, individual budgets, supports for self-direction, participant protections and quality management) should be added. Within Vocational Rehabilitation, the Division utilizes Title 1 funds, funds that require progress toward the goal of "fostering an environment that promotes informed choice". The Division could conduct a project related to consumer-direction utilizing Title 1 funds to address this goal.

Quality Management Committee: One suggestion is that DHHS establish a quality management committee specifically to track key performance indicators in self direction, across populations. Initially, such data will have to be drawn from separate "stove pipe" QA systems but can be refined and standardized over time. Members of the committee could include key Division staff as well as consumers, families and advocates. The strength of this suggestion is that it would enable the Department to learn from all of the experience in self-directed supports so as to enable further policy development in this arena.

APPENDIX A:
PROPOSED AMENDMENTS TO SECTION 143B OF THE NORTH CAROLINA STATUTES

Note: The Department of Health and Human Services is established by § 143B. 136-216. Within this statute, the following proposed amendments would occur in two places. One amendment would insert language into the Department's enabling statute; the other would insert language to enable the Secretary to execute rulemaking.

Current language
"§ 143B-137.1. Department of Health and Human Services – duties.

> *It shall be the duty of the Department to provide the necessary management, development of policy, and establishment and enforcement of standards for the provisions of services in the fields of public and mental health and rehabilitation with the intent to assist all citizens – as individuals, families, and communities – to achieve and maintain an adequate level of health, social and economic well-being, and dignity. Whenever possible, the Department shall emphasize preventive measures to avoid or to reduce the need for costly emergency treatments that often result from lack of forethought. The Department shall establish priorities to eliminate those excessive expenses incurred by the State for lack of adequate funding or careful planning of preventive measures. (1997-443, s. 11A.3.)"*

§ 143B-137.2. Proposed amendment establishing and promoting Consumer Self-Directed Services

> The State of North Carolina affirms the authority and responsibility of citizens to exercise control over their lives, including the manner in which services and supports are furnished to them. Self-direction of services and supports by people with disabilities or elders is recognized as a way for these citizens to exercise choice and control and is supported as one option under a continuum of services offered under the Department. Self-direction at a minimum includes personal control of the type of services to be received, the manner in which the services are delivered, and the selection and oversight of the person(s) providing the services and supports.

The proposed amendment to provide for Secretary rule-making would be inserted as follows:

§ 143B-139.1A. Secretary of Health and Human Services to adopt rules applicable to Consumer Self-Directed Supports

> The Secretary of the Department of Health and Human Services may develop, implement and expand voluntary options for individuals to self-direct services across the full range of programs under the management of the department. In furtherance of this objective the Secretary may adopt and enforce rules; may implement new service financing mechanisms; may amend or waive department rules and regulations under the Secretary's authority; and may establish standards, quality measures and performance benchmarks related to the implementation and expansion of self-directed service throughout the department.

APPENDIX B: GENERAL STATUTES & REGULATIONS REVIEWED

STATUTES

GS 143B	Dept. of Health & Human Services & Divisions
GS 143-545.1	Vocational Rehabilitation
GS 122C	Mental Health, Developmental Disabilities and Substance Abuse Services
GS 108A	Social Services
GS 90-171	Nursing Practice Act
GS 131D	State/County Special Assistance

REGULATIONS

Division of Mental Health, Developmental Disabilities, and Substance Abuse Services

- 10A NCAC 26D - Department of Corrections standards for MH and DD services
- 10A NCAC 27B - Social Services Block Grant (T-XX) rules
- 10A NCAC 27C - General policies and procedures
- 10A NCAC 27D - Rights related to restrictive interventions
- 10A NCAC 27E - Protections and requirements related to restrictive interventions
- 10A NCAC 27F - Basic rules for 24-hour facilities
- 10A NCAC 27G - MHDDSAS mega-rules for community programs/Area Authorities
- 10A NCAC 27H - Admissions to non-restrictive facilities
- 10A NCAC 27I – LME administrative requirements
- 10A NCAC 28 - State operated MHDDSA facilities

Division of Medical Assistance

- 10A NCAC 21A – 21D Medical Assistance Administration
- 10A NCAC 22A – 22O Medical Assistance Eligibility

Division of Facility Services

- 10A NCAC 13J – Licensing of Home Care Agencies

Division of Services for the Blind

- 10A NCAC Chapter 63

Division of Services for the Deaf and Hard of Hearing

- 10A NCAC Chapter 27

Division of Aging and Adult Services

- 10A NCAC Chapter 5 (Aging)
- 10A NCAC Chapter 6 (Aging)
- 10A NCAC Chapter 67 (Social Services)
- 10A NCAC Chapter 71 (Adult & Family Support)

Division of Vocational Rehabilitation Services

- 10A NCAC Chapter 89

Unlicensed Personnel: Nurse's Aides

- 21 NCAC Chapter 36

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APPENDIX C: DOCUMENTS REVIEWED

- *Today's Choice: Tomorrow's Path, An Evaluation of the System for People with Developmental Disabilities in North Carolina, a report prepared by HSRI for the NC Legislative Oversight Committee on MH/DD/SAS Reform*
- *Choice, Change, Community: Charting a New Course for Customer – Driven Long-Term Supports for North Carolinians with Developmental Disabilities, 1997*
- *The Robert Wood Johnson Foundation Self-Determination Initiative: Final Impact Assessment Report, November 2001*
- *Self-Determination Efforts for People with Developmental Disabilities in North Carolina: A Report on Three Years of Observation and Evaluation, June 2003*
- *Vulnerable Populations. Determining Personal Care Consumers' Preferences for a Consumer-Directed Cash and Counseling Option: Survey Results from Arkansas, Florida, New Jersey, and New York Elders and Adults with Physical Disabilities, June 2004*
- *CMS Systems Change Grants, 2001 and 2002*
- *The State Plan 2001* and subsequent yearly updates, and *DMHDDSAS Blueprint for Change 2004-2005*
- *Independence Plus Waiver in NC 2004-2005*
- The 99-660 North Carolina Community Mental Health Block Grant Plan , SFY 2004-2005
- The North Carolina Substance Abuse Prevention and Treatment Block Grant Plan;
- Licensing requirements and other quality assurance policies, procedures and regulations; relevant to person-driven supports
- CAP/DA-Choices HCBS Waiver Application
- Piedmont Innovations HCBS Waiver Application
- CAP/MR-DD HCBS Waiver Renewal Application
- CAP/DA Manual
- Division of Medical Assistance *Community Care Provider Manual* (Section 6 – Personal Care Services (PCS); Section 10 – Community Care Alternatives for Persons with AIDS; Section 11 – Community Alternatives for Children (CAP/C); Section 12 – Community Alternatives for Disabled Adults (CAP/DA))
- North Carolina Medicaid State Plan
- Office of the State Auditor. *Performance Audit: Community alternatives for Disabled Adults (CAP/DA)* (October 2004)
- Person-centered planning templates
- National Core Indicators, Phase VI Final Report 2003-2004, published January 2005
- North Carolina Department of Health and Human Services Division of Mental Health, Developmental Disabilities and Substance Abuse Services Communication Bulletin #34 Person Centered Planning, and Communication Bulletin # 35 Policy Guidance
- Current plan for SFY 05 MH Trust Fund Utilization

- Division of MHDDSAS performance contracts with LMEs + all attachments
- Latest draft of the Medicaid service definitions (Aug and Oct, '04)
- Notes for New Permanent Staff Competency Rules (undated)
- Memo from MHDDSAS about rulemaking issues related to self-direction (related to the new DD waiver - Independence Plus)

APPENDIX D: REGULATION & POLICY FINDINGS AND RECOMMENDATIONS BY DHHS DIVISION

DIVISION OF MENTAL HEALTH, DEVELOPMENTAL DISABILITIES AND SUBSTANCE ABUSE SERVICES

Issue	Regulation Citation	DMHDDSAS Rule Alignment with Self-Determination	Recommendations
Facility Definition	10A NCAC 27G.0103 General Definitions	(27) – Facility definition from 122C-3 carried verbatim from statute into the regs and would seem to cover an individual hired directly by a consumer. This definition of an individual defined as a facility is potentially confusing as to whether an individual staff must meet requirements of facilities or licensable facilities. (47) "Provider" = individual (not specifically a facility) – may be a little more flexible than the statute (53) The definition of "service" does not refer to "facilities" - may provide some room for self-direction Language in the regulations, and corresponding language in statute, reflects facility-based models.	Tinkering with the regulations and service definitions will not be effective. There probably needs to be a new section of regulations which could say "Notwithstanding the provisions of any other regulations or requirements to the contrary…", and then would proceed to establish a new body of implementation standards, program requirements, performance expectations, monitoring and QM/QI practices, etc. designed specifically for self-directed services. However, for small-scale self-determination projects, DHHS could use the LME provider endorsement process, a few of the new Medicaid service definitions, and waivers by the Rules Commission or Division of Facility Services with regard to rules posing barriers.
	10A NCAC 27G.0201 Governing Body Policies	In general, these policies assume a "facility" and a formal organizational structure for everything from admission policies to record keeping to quality management. This assumed structure may not fit well with self-direction of services, uses of intermediaries, etc. This raises the whole question of who will be responsible for these things in a self-direction modality. Nothing within these rules either stimulates or prevents self-determination.	

Issue	Regulation Citation	DMHDDSAS Rule Alignment with Self-Determination	Recommendations
Provider Qualifications	10A NCAC 27G.0202 Personnel Policies	As with the governing body policies, the personnel requirements assume a "facility" that has "staff" with formal job descriptions, etc. – these may not be applicable to self-direction and to consumers or intermediaries being employers of record.	
	10A NCAC 27G.0203 Competencies of qualified professionals, etc.	The new competency-based approach to credentialing professionals and paraprofessionals has some opportunities for incorporation of principles and competencies related to self-directed service approaches. However, the supervision requirements for paraprofessionals may be difficult to accomplish in a self-directed service modality.	The supervisory requirement could be met by qualified professionals in Community Support conducting the supervision, or Targeted Case Management in DD services. Yet if the person is to be truly the one providing the supervision of staff, the quality management function of assuring client health & welfare could be provided by assisting the person to develop supervisory skills, identify risk and potential harm, and take appropriate intervention where warranted, reducing the necessity of requiring professional-level supervision of direct care staff. This activity may be reimbursable under the proposed waiver, as well as under Targeted Case Management or community support in Medicaid. There will be new guidelines developed to implement these new competency standards, and these may present an opportunity for incorporation of provisions friendly to self-direction.

Issue	Regulation Citation	DMHDDSAS Rule Alignment with Self-Determination	Recommendations
Service Planning	10A NCAC 27G.0205 Assessment and treatment planning	There is no mention here of consumer choice or planning related to self-direction. Nor is there a reference to assessment of the desire or potential of the consumer to self-direct all or part of services.	To support self-direction, this section would need to be amended or superseded to incorporate appropriate assessment of client interest and needs for support to self direct. This could first be explored in small scale demonstration programs, and possibly reflected in new regulations devoted solely to self directed services.
	10A NCAC 27G.0206 Client records	This section governs records for clients admitted to a "facility." Would the LME be considered the "facility" for consumers electing self-direction or otherwise not simply admitted to one facility? Also, there is no mention of self-direction or recordkeeping standards supportive of self-direction in this section.	
	10A NCAC 27G.0208 Client services	Subpart (a)(3) states" clients participate in planning or determining activities". This is about as close as the regs get to a consumer role in self-direction or choice of services. However, this only applies to "facilities", and seems to be directed at social-recreational activities more than self-direction of services and supports.	
	27 I .0202	Provide for client/family participation in and approval of service plans; rules do not foster assessment of person's self-direction desires or skills, nor specify planning for self-direction or services and supports leading toward self-direction.	
Medication Requirements	10A NCAC 27G.0209	Medication requirements – specifically for consumers who may need prompting or assistance to self-administer medications – can be a barrier to self-directed services. Although not specifically stated, the specific requirements in this section seem to apply to 24 hour facilities, not to consumers living at home and self-directing services. However, without clarification the requirements could function as a barrier to self-direction for consumers needing assistance with medications.	Individuals self-directing services who are prescribed medications will need to be assessed regarding their capacity to manage procurement, taking as prescribed and reporting benefits & side effects. Such a risk assessment & need for supports for safe medication administration would be covered in the individual's service plan. Staff providing medication prompts or other

Issue	Regulation Citation	DMHDDSAS Rule Alignment with Self-Determination	Recommendations
			supports under the supervision of a self-directing consumer may need additional training in medication administration, handling, and medication errors, etc.
Quality Management	10A NCAC 27G.060ff	These sections cover Area Authority (LME) monitoring requirements for facilities and services. In general, they assume a facility-based provider system - - individual practitioners are included only if they are licensed or certified to practice in NC. There are no provisions that would include intermediaries or direct service staff employed by a consumer or intermediary. A process for incident reporting and investigations, complaints and grievances, etc. for self-directed services is not anticipated by or included in these provisions.	New regulations or policies and procedures governing self-directed services should define the LME's special functions with regard to monitoring, compliant review and resolution, etc.
Incident Management	27 I	The client protection and incident investigation provisions reflect the LME role and the presence of a Citizens Advisory Committee at the LME level.	
Licensing – Waivers	10A NCAC 27G.0800	This section contains the specific requirements for waiver of licensing rules by the Division of Facility Services, and other rules by the Rules Commission.	Pending development of new rules for self-directed services, the waiver provisions might be used in a limited manner to allow small scale demonstrations of self-directed service approaches to be implemented.
Service Definitions (Current)	10A NCAC 27G.0501 Required Services	The list of 13 mandatory services does not include any reference to or provisions for consumer self-direction, peer supports, fiscal intermediary services, supports coordination (although this may be included under case management). On the theory that people mostly only do what they are required to do, this list of required services provides no incentive for LMEs or providers to move towards self-directed services approaches.	While these definitions are slated to be changed when the new service definitions are put in place, the revised service definitions do not cover the components of self-directed services. [See items related to new service definitions covered below.]

Issue	Regulation Citation	DMHDDSAS Rule Alignment with Self-Determination	Recommendations
	10A NCAC 27G.1100 through 27G .6400	These sections are reported to be superseded by the new service definitions once implemented. See comments below on the draft new service definitions.	
Service Definitions (Aug/Oct 2004 draft of new service definitions)	General	The definitions define "practitioners" as being employed by MHDDSA provider agencies – there is no reference to providers/practitioners being employed by consumers or intermediaries	
	Community Support	Peer supports are included in the definition, but apparently they would have to be employed by a "qualified" MHDDSA provider organization (see 10A NCAC 27I for provider certification process.) Paraprofessionals as defined in 10A NCAC 27G.0104 are included, but these are not necessarily peer supports, and still must be supervised by a "qualified professional."	This service definition could incorporate supports coordination for people meeting the medical necessity criteria (serious mental illness or co-occurring mental illness/substance abuse). The Community Support Team could perform a supports coordination but not a self-directed service if using the definition of self-direction proposed by this study.
	Mobile Crisis management	The service definition does not include anything about crisis plans, advance directives, etc. that could assist consumers to exercise choice and self-direction while in crisis.	
	Diagnostic assessment	There is no mention of assessing strengths, abilities or choices related to self-direction.	
	Community Support Team	No mention of peer supports or self-direction. However, the definition does state that a "certified peer support specialist" should (not must) be included on each team. A definition of "certified peer support specialist" in the regs or draft guidelines for competency based credentialing was not found.	

Issue	Regulation Citation	DMHDDSAS Rule Alignment with Self-Determination	Recommendations
	Developmental therapy	Includes "individually designed training…in activities to strengthen …developmental functioning in areas such as self care, independent living and self advocacy…." This service might appropriately be self directed, but the definition specifies that the service(s) must be delivered by a provider organization certified under 10A NCAC 27I.0208. Thus, it seems that neither the consumer nor an un-certified intermediary could be the employer of staff providing this service under this definition. When a paraprofessional provides this service, they must be supervised by a qualified professional or associate professional (not the consumer.)	
	Targeted Case Management	This definition could cover supports coordination, person centered planning, etc. The targeted case manager is prohibited from delivering any direct services to the consumer. And the agency providing case management is prohibited from providing services other than case management to the individual. This could limit some activities of intermediaries wishing to provide case management as well as providing fiscal intermediary services,. The federal CMS has been asserting the limited roles of TCM, focusing on service planning, linkage and monitoring. Thus while TCM could be part of person centered planning, monitoring, quality management and assuring participant health and welfare, teaching a person to manage his/her services is outside the reimbursable functions of TCMs. In addition, this service is limited to individuals who have developmental disabilities, so it will not be helpful for individuals with other disabilities.	It might be useful to establish another service definition such as Supports Brokerage, that would serve the function of teaching a person to manage his/her services, which is outside of the purview of a TCM. In this case, a fiscal intermediary agency could also provide Supports Brokerage and the TCM could still be a separate provider, as the TCM definition is currently written. This would work for individuals with developmental disabilities but still does not address other disability areas.

Issue	Regulation Citation	DMHDDSAS Rule Alignment with Self-Determination	Recommendations
Qualified provider	27I. 0207	Includes a reference to 'facilitate client choice' but this appears to reference choice among providers of services, not choice to self-direct services.	For self-directed supports,the offer of a choice to individuals regarding interest in self-determined services & need for supports will need to occur.
	27 I .0208	Allow endorsement of provider agencies that are neither licensed by the state nor accredited by a national accrediting body. Under the service definitions Medicaid seems to be requiring national accreditation within 3 years for providers 'endorsed' by LMEs. There is still no category or provision that specifically provides for certification or endorsement of individuals or organizations that deliver staff for self-directed services or provide fiscal intermediary functions. There is nothing in the provider endorsement provisions that anticipates a LME role in doing criminal background checks or other verification or quality monitoring functions vis-à-vis staff employed by consumers or intermediaries in a self-direction mode.	Across the board DHHS needs to consider criminal background checks of putative staff be they agency or independent providers. Background check report should be quickly secured. A process for managing client choice even when violations are found should be put in place.

DIVISION OF MEDICAL ASSISTANCE

Issue	Regulation Citation	DMA Rule Alignment with Self-Determination	Recommendations
Program Design: CAP/MR-DD	CAP/MR-DD Manual, as revised 1/1/04; CAP/MR-DD HCBS waiver renewal application	CAP/MR-DD as presently designed and redesigned in the HCBS waiver application does not incorporate all the hallmarks of self-direction: i.e., person-centered planning, individual budgets, consumer control and management of services and supports.	Proceed with the design and implementation of the Independence Plus "supports waiver." Examine the potential for revamping CAP/MR-DD in the future to incorporate consumer-directed opportunities into CAP/MR-DD.
Program Design: CAP/DA	Chapter 12, DMA Community Care Manual; CAP/DA Manual	CAP/DA does not incorporate any of the hallmarks of consumer-direction. Management and delivery of CAP/DA services is the responsibility of case managers/provider agencies. CAP/DA does not provide waiver participants the opportunity to hire, supervise and fire in-home aides or respite workers. Essential in-home services may only be furnished by the employees of licensed Home Care agencies.	Based on experience with CAP/ - Choice, revamp consider revamping CAP/DA to incorporate consumer-direction opportunities.
Program Design: CAP/C	Chapter 11, DMA Community Care Provider Manual; CAP/C Manual	CAP/C does not incorporate any of the hallmarks of consumer-direction. Management and delivery of CAP/C services is provider-managed and does not provide a consumer-directed option.	Consider redesigning CAP/C to establish consumer-directed opportunities, especially with respect to the provision of in-home aide and respite services.
Program Design: CAP/AIDS	Chapter 10, DMA Community Care Provider Manual; CAP/AIDS Manual	In its current design, CAP/AIDS does not incorporate any of the hallmarks of consumer-direction. Services that can readily be consumer-directed (in-home aide and respite) by consumers who choose it instead must be provided by the employees of licensed Home Care agencies.	Consider redesigning CAP/AIDS to establish consumer-directed opportunities, especially with respect to the provision of in-home aide and respite services.
Program Design: PCS & PCS Plus	Chapter 6, DMA Community Care Provider Manual; North Carolina Medicaid State Plan (Attachment	PCS/PCS Plus are designed along traditional, provider-managed lines. Providers are limited to licensed Home Care agencies. Does not provide for PCS/PCS Plus recipients to opt to directly employ in-home aides. Care planning is performed by nurses; no provision for consumer-initiated	Consider redesigning the program to clearly provide for options for consumer employment of aides and consumer scheduling of aides.

Issue	Regulation Citation	DMA Rule Alignment with Self-Determination	Recommendations
	3.1-A.1, approved 2/26/04); 10A NCAC 22O.0120	modifications to the care plan. Services must be recommended by a physician and supervised by a nurse. Federal law and regulations do not require either.	
Home Health State Plan	NC DMA, *Community Care Provider Manual*, Chapter 5 – Home Health Services	Diapers and other medical supplies required by people in the community are furnished under the Medicaid home health state plan benefit and must be obtained through home health (home care) agencies. In order to obtain diapers and other medical supplies, it is necessary to demonstrate that the item/supply is "medically reasonable and necessary for treatment of a patient's illness or injury [and that] the supply has a therapeutic or diagnostic purpose for a specific patient." The supply must be ordered by a physician and included in the person's home health plan of care. With respect to diapers, a 90-day supply may be authorized; in order to obtain more diapers, a home health nurse must conduct a follow-up evaluation. The problems that have been encountered in obtaining diapers include: ▪ The reluctance of home health agencies to serve as a mere conduit for securing diapers when the home health agency does not furnish other services to the person; ▪ The expense associated with the evaluation in order to authorize a new 90-day supply; ▪ Having to work through home health agencies has been identified as at odds with self-direction; ▪ Many individuals require diapers as a result of chronic disability but present policy does not permit standing authorizations for diapers; and,	North Carolina's present policies are consistent with federal policy when supplies are delivered as a home health benefit. However, North Carolina clearly may consider the option of restructuring its coverage of supplies to be a freestanding benefit. This potentially would reduce costs (in the case of persons who require diapers on a permanent basis due to chronic disability) since requiring that diapers be obtained through home health agencies adds potentially unnecessary costs. At the same time, there may be drawbacks to restructuring the Medicaid medical supply benefit, including losing the benefit of nurse visits to check on the heath status of the individual. If North Carolina wants to provide for an alternative avenue for obtaining diapers and other medical supplies that does not involve using home health agencies, it could provide such an avenue through its waiver programs. A simple way of distinguishing waiver coverage of diapers from State plan coverage would be permitting the provision of

Issue	Regulation Citation	DMA Rule Alignment with Self-Determination	Recommendations
		▪ The difficulty in accessing home health services in rural North Carolina.	diapers under the waiver for individuals who are not receiving home health services.

DIVISION OF AGING & ADULT SERVICES*

Issue	Regulation Citation	Aging & Adult Services Alignment with Self-Direction	Recommendations
Nurse delegation	10A NCAC Chapters 5 – 6 Section .0400 (Unlicensed Personnel: Nurse Aides) of Chapter 36 (Board of Nursing) of Title 21 (Occupational Licensing Boards)	Makes clear that nurses may in some instances transfer to a competent individual, referred to as a "nurse aid," the authority to perform a selected nursing activity in a selected situation. But in all cases it is the nurse who retains accountability for the delegation. Moreover, the qualifications of the nurse aid are clearly spelled out. Furthermore, the Board of Nursing is to be the determining authority on those nursing care activities which may be delegated to unlicensed personnel. Interviewed stakeholders expressed strong reservations about new or modified language for the Division of Aging and Adult Services' existing rules addressing in-home personal assistance services.	These rules pertain to home based care and thus are free of the facility bias in other regulations but still retain a medical model of service delivery focus.

Issue	Regulation Citation	Aging & Adult Services Alignment with Self-Direction	Recommendations
	10A NCAC Chapters 5 – 6 Section .0400	The regulations are silent about delegation of patient care activities. The one exception is a statement that "Listing on a Nurse Aid Registry is not required if the care is performed by clients themselves, their family or significant others or by caretakers who provide personal care to individuals whose health care needs are incidental to the personal care required." Thus as long as the care required is for patient care activities – i.e., health care is incidental to the care required – licensure does not come into the picture. Rather, the consumer is the ultimate decision maker and can direct the care in settings such as his/her home or an employment arena. A potential barrier exists however if a program is designed with the option for a fiscal agent to be the employer of record; then the licensure rules come into play. The main question is who the employer is -- if it is the consumer who is the employer of record and s/he lives at home and asks a nurse or even a home care agency to come in, then the consumer is still in charge.	Division leadership is developing new rules that provide for consumer directed services that are parallel to but separate from the existing rules. We concur with this approach and recommend developing new rules allowing for consumer-directed in-home personal care services. Consumer-directed should apply to the elder person him/ herself except in those programs such as Family or Caregiver Support, where consumer-directed will apply to the family members of the elder person.

***** Rules reviewed were specific to the Division of Aging. Although the Division of Aging and the Adult and Family Services Branch have merged into the Division of Aging and Adult Services, at the time of this review regulations were separate.

ADULT AND FAMILY SUPPORT*

Issue	Regulation Citation	Adult and Family Support Alignment with Self-Direction	Recommendations
Guardian Services	10A NCAC 71 B .0101	This is a very good rule; it requires S-D to the extent possible including that the guardian petition the court to release a ward from guardianship when restored to competency.	
Person Centered Service Plan	10A NCAC 71 C Adult Placement Services	.0103 Service Planning. Notes that client & family strengths and goals are to be included in the service plan and the client involved as much as possible.	
Social Services Block Grant	10A NCAC 71R .0101	Funded Services include many reimbursable services within the 37 listed services that could be contained within an expansive designation of S-D supports. However there are no specific references to enhancing client and/or family capacity to self-direct, or hire/fire/supervise own staff, etc.	Consider expanding funded services to specifically allow for components of self-direction such as hiring, supervising, or firing staff.
Service Definitions	10A NCAC 71R .0902 Community Living Services; .9305 Employment & Training Support Services	Notes target population as individuals who are 'mentally retarded' and while not a barrier to self-directed supports does not align with People First language that is sensitive to clients' preferred terminology. Using People First language helps to create environments conducive to self directed services. (This was the only service definition linked to service planning.) Notes that In-Home Aide Services are "paraprofessional services". Does the term paraprofessional limit the choice of provider a person may select to render the home management, personal care, or supervision tasks?	Consider updating language of "mentally retarded" to People First language such as "person with an intellectual or cognitive impairment".

DIVISION OF VOCATIONAL REHABILITATION SERVICES

Issue	Regulation Citation	Vocational Rehabilitation Alignment with Self-Direction	Recommendations
	10A NCAC Chapter 89	There is nothing in the Voc Rehab rules that refers to self-direction directly. However, there is some language that may not be conducive to an expansion of self-directed services within the agency. For instance, all vendors are referred to as agencies or organizations; individual service providers are not necessarily prohibited, but neither are they specifically allowed.	
Choice & Control	89D – Standards for Facilities and Providers	The rules also suggest a preference for licensed and accredited vendors.	
	Chapter 2. Section 2-18-3	In rule all vendors are referred to as agencies or organizations; individual service providers are not necessarily prohibited, but not allowed for either. And there is a regulatory preference toward vendors that are licensed or accredited by some public authority	
	89D. Section .0300 – Standards for Providers of Services	Clients are only allowed to "freely choose" their own physician. There is no mention of "freely choosing" any other provider.	
Person Centered Service Planning	*Policy* - Casework & Service Delivery Chapter 5. Section 5-2-3	"The services planned to achieve the IL goals shall be recorded on the Individualized Plan for Independent Living, along with the anticipated initiation date of the service, and the service provider chosen by the individual." Contains elements of person centered planning and client choice and control.	
Choice & Control	*Policy* - Casework & Service Delivery Chapter 2. Section 2-1-2	"The purpose of the Independent Living Rehabilitation Program (IL) as authorized by Chapter 1 of Title VII of the Act is to promote a philosophy of independent living including consumer control, peer support, self-help, self-determination, equal access and individual and system advocacy to maximize the leadership, empowerment, independence, and productivity of individuals with significant disabilities and to promote and maximize the integration and full inclusion of individuals with significant disabilities in the mainstream of American society."	

Issue	Regulation Citation	Vocational Rehabilitation Alignment with Self-Direction	Recommendations
Choice & Control	*Policy* - Casework & Service Delivery Chapter 2. Section 2-18-3	The Division has made a serious attempt to support self-direction of "capable" clients, particularly in regard to the management of personal assistance services. The language used in policy related to the Independent Living Rehabilitation Program is very conducive to self-direction. Clients of both the Voc Rehab and IL programs are expected to hire, fire, pay, and manage their personal assistance attendants, as long as they do not receive payment of these services from the Medicaid program. The Division provides training to recipients of Division-sponsored personal assistance services. However, personal assistance is restricted to persons who are capable of independently managing the employer/employee relationship in both the Voc Rehab and IL programs. There is no allowance for a fiscal intermediary in the IL program. Clients within the VR program must be capable of managing all aspects of employer/employee relationship; but if incapable is allowed to employ a qualified bookkeeper or accountant at the Division's expense. This sounds almost like a fiscal intermediary/financial management component but it would need to be determined how this is being operationalized to determine whether it meets the needs of the participants.	Examine whether the Division wants to continue designation of clients as 'capable' of self-direction. Consider utilizing Title 1 funds to fund a demonstration project using a fiscal intermediary for clients interested in self-directing services but not able to independently manage all of the fiscal details. It is acknowledged that to use Title I funding, the project would have to be implemented for individuals to receive an employment outcome and that personal assistance would have to be provided only while the individual is receiving other VR goals. There might also be opportunity to expand self-direction in services beyond personal assistance to include job coaches, note takers, interpreters, etc., as allowed within federal regulation.

DIVISION OF SERVICES FOR THE BLIND

Issue	Regulation Citation	Services for the Blind Alignment with Self-Direction	Recommendations
	10A NCAC 63D. 0601 Responsibilities of Agency.	Provides that the agency shall provide assistance and opportunities for the consumer to express his/her rights and requires agency to employ methods that do not infringe on consumers' rights.	Affirms consumer-direction and empowerment.
VR/ Work	10A NCAC 63 F .0401 Benefits.	When determining economic need the Division is to consider all other benefits available to the consumer available to cover the cost of any vocational rehabilitation services but exempts counseling and guidance, *including information and support services to assist the applicant or consumer in exercising informed choice;…*	Affirms consumer-direction and empowerment.
VR/ Work	10A NCAC 63 F .0502 Order of Selection for Services	Addresses prioritization for services excluding Independent Living Rehabilitation Program. To prioritize those individuals with significant disability whose impairment limits two or more functional capacities in terms of employment; the functional capacities include the person's ability to self-direct.	DSB may want to re-examine this prioritization of services to those who are able to self-direct. Prioritization probably arises from lack of resources; however, an important element of rehabilitation philosophy is to provide support so that a person gains capacity.
Person Centered Service Plan	10A NCAC 63 F Vocational Rehabilitation	Job placement in competitive integrated setting is the goal of VR program. Individualized Plans for Employment are developed that are, "to the greatest extent possible", consistent with the consumers skills, interests, needs, and informed choice.	
Choice & Control	Policy manual	With respect to individuals who are blind, family members can provide paid supports but only as In Home Management Service workers (non-personal care) and only if they have to give up other paid employment. This a particular constraint given that such In Home Mgmt work is currently limited to up to 5 hours a week and the pay is minimum wage or county prevailing rate.	

Issue	Regulation Citation	Services for the Blind Alignment with Self-Direction	Recommendations
	10A NCAC 63F Scheduling Notice of Administrative Review and Mediation	Requires mediators to arrange mediation sessions at a date, time and location convenient for the applicant/consumer as well as for the agency representative. Consistent with client empowerment.	

DIVISION FOR SERVICES FOR THE DEAF AND HARD OF HEARING

Issue	Regulation Citation	Services for the Deaf and Hard of Hearing Alignment with Self-Direction	Recommendations
Intake	10A NCAC 17D .0205	Requires regional centers to provide assistance to applicants in completing application forms when requested. This type of outreach builds trust with the public and is empowering to clients.	Consider extending this type of hands on support to other Divisions.

DIVISION OF SOCIAL SERVICES

Issue	Regulation Citation	Social Services Alignment with Self-Direction	Recommendations
	10A NCAC Chapter 67A .0202 (4) Exceptions for Notification	Regulations do not provide for notification of action when the county department of social services has applied for services on behalf of an individual who is incompetent or incapacitated. Even when a person is incompetent in some areas of decision making, s/he typically retains some areas of competency. Furthermore, providing notice is a due process protection and offers clients dignity and the opportunity to make preferences known.	Review regulations to ensure that clients are apprised of services applied for on their behalf.