

The Arc of North Carolina Guardianship Statement
February 2014

Good morning. My name is Julia Adams and I am the lobbyist for The Arc of North Carolina. We would like to thank the chairs and members of the committee for inviting us to speak on the topic of guardianship.

The Arc of North Carolina has been providing advocacy and services to people with intellectual and developmental disabilities since 1953. The Arc believes that all people with intellectual and developmental disabilities have strengths, abilities and inherent value, are equal before the law, and must be treated with dignity and respect.

Today we have been asked to address several topics under guardianship. The first is an overall look at guardianship by The Arc of NC, followed by issues that developed as we moved to the 1915b/c waiver and in closing our statement on parents as providers.

The Arc of North Carolina is a provider of guardianship services. It is important to recognize that in North Carolina there are basically three types of guardianship: (1) Guardianship of the Person, (2) Guardianship of the Estate, and (3) General guardianship. A guardian of the person has the authority to make decisions in most areas of the ward's/individual's personal life. On the other hand, a guardian of the estate has the authority to manage the ward's income and property. A general guardian has the duties of both the guardian of the person and the guardian of the estate. State law allows for a clerk of court to limit the duties of the guardian to those areas of need only. This enables the ward to still have control over specific areas of their lives.

As an organization we provide guardianship under our LIFEguardianship program. We utilize a corporate guardianship model in which The Arc of NC board becomes guardian for individuals, when there is no family member or other individual able or willing to do so. However, guardianship is restrictive and as such should never be taken lightly. Alternatives to guardianship should be pursued before the initiation of guardianship of the person, of the estate, or both. Alternatives include: Power of Attorney; Durable Power of Attorney; Health Care Power of Attorney; Declaration Regarding Natural Death (DNR or Living Will); Advance Instruction for Mental Health (AIMHT); Social, Habilitation, Case Management and Advocacy Supports; Circle of Friends; Representative Payee for Social Security and other pensions/benefits; and/or Trust.

The mission of LIFEguardianship is to advocate and ensure that person-centered supports and services are provided in the least restrictive/intrusive manner possible; that the personal preferences and desires of the individual/ward are important and given serious or total consideration; that every opportunity is made available to the individual/ward to exercise all rights within his or her judgment

and comprehension, allowing for the possibility of error to the same degree allowed persons who are capacitated. Thus, even with a guardian, an individual should participate as fully as possible in all decisions that affect him/her. In addition, guardianship should be reviewed periodically, at least annually, and a decision made as to whether an individual's/ward's rights need to be partially or fully restored.

LIFEguardianship Supports and Services are available in every county in North Carolina. It is provided only when other alternatives have been pursued and are found not to be appropriate. Individuals may have a developmental disability, chronic mental illness, or be elderly or substance abusers. The Arc of North Carolina employs 25 full time guardianship specialists and two part time specialists for a total of 27 staff. Currently we have 772 protégés or wards in our program. Our current caseload is 1:32.

Excellent training and stable funding is critical for a robust guardianship program. Over the years we have seen significant cuts to the guardianship budget as well as a shift in which agencies or departments we contract with to provide these critical services.

Prior to the mergers and changes in the LME/MCO system, each individual LME contracted directly with The Arc of NC to provide guardianship for people with mental illness and developmental disabilities served under the LME system. As LMEs merged together and into a managed care system, one of the unintended consequences affected the contracting of guardianship services with third party entities like The Arc of North Carolina. A legal ruling in Rowan County by Judge Calvin E Murphy stated that “due to federal Medicaid waivers, specifically in PBH (Piedmont Behavioral Health now Cardinal Innovations) the managed care waiver, an actual or potential conflict of interest exists that presents PBH from being appointed as the guardian of any PBH consumer and as a result of this actual or potential conflict of interest PBH cannot contract its guardianship appointments to a third-party entity.” This legal decision was then applied to all of the LME/MCOs.

As a consequence of these mergers guardianship contracts were cancelled and consumers were transitioned into contracts with local Department of Social Services agencies or in some cases, as seen with The Arc of NC, the contracts were moved to the Division of Aging. Many of our concerns were the actual supports put in during these transitions and that for the developmental disability population the skill set needed to advocate and work with this population may not have been readily available at all local DSS offices. In addition this shift caused significant issues in increased administrative services if we were required to contract with multiple DSS offices in all 100 counties. In the end, The Arc of North Carolina, was able to secure new contracts for majority of our wards through the Department of Aging.

In addition to the transferring of wards and contracts under the LME/MCO mergers there has always been concern amongst advocates on establishing a dedicated

funding source for guardianship services. The Arc of North Carolina agrees that this is an important part of our advocacy agenda. This year's state budget brought together state dollars and federal dollars to fund guardianship in our state under one line item and full Social Services Block Grant funding under a separate line item. When the federal government experienced its shut down, guardianship funding in our state nearly came to halt. This instability caused significant concern to organizations that provide guardianship services throughout the state. We encourage the General Assembly to minimize any further significant changes to this fragile system including how we fund it and who handles the contracts for it.

The Arc of North Carolina has advocates for and with parents of children with intellectual and developmental disabilities. The issues of parents as providers is a critical policy issue for our membership.

As an advocacy organization we are also very engaged with the ongoing discussions regarding compensating parents and providers of services for their children. Historically we have supported the option of compensating parents as providers. Families of people with developmental disabilities have and will continue to be critical support to their children with developmental disabilities. The Arc of North Carolina reaffirms its commitment to families to receive family support dollars to provide care to their children in the home.

Often families are placed in the position of becoming the primary paid caregiver for their child due to the lack of high quality direct support workforce. Parents who have provided this service have done so because of their interest in ensuring high quality service to their loved ones.

The Arc of North Carolina does understand the need for the State of North Carolina to regulate services that utilize funds from the Innovations program. We are very aware that there is a need to also protect the voice of the child or adult child in this arrangement and we would advocate for a third party to sign off on any person centered plan to ensure that there is a neutral party that can mediate the individuals needs. We look forward to working with members of the legislature, department and providers to come to a comprehensive solution that will allow for parents to provide services while protecting the needs of the child.