

TESTIMONY OF HARC, INC.  
WITH RESPECT TO SECTION 1115 DEMONSTRATION DRAFT WAIVER APPLICATION  
TO THE HUMAN SERVICES AND APPROPRIATIONS COMMITTEES  
JULY 24, 2012

Good morning Senator Harp, Senator Musto, Representative Walker, Representative Tercyak and distinguished members of the Appropriations and Human Services Committees. I am Andrea Barton Reeves, Vice President of Administration for HARC, Inc. We have proudly supported people with intellectual and related disability and their families for over 60 years. We write to express our concerns about the Section 1115 Demonstration Draft Waiver Application. We are concerned that the proposal to exclude Low Income Adults from Medicaid eligibility if their families hold \$10,000 or more in assets (excluding their home and car) will have an unintended adverse impact the parents and guardians of people with intellectual disability.

Adding the asset test of \$10,000 as a threshold requirement to limit access to Medicare benefits would place parents and guardians in the impossible position of either limiting assets to provide for their child's healthcare, or acquire assets to care for their children in the future and risk having no affordable healthcare during their children's lifetimes. This is an impossible choice for parents and we ask the Committees to consider this impact on families of adult children with intellectual disability before imposing this asset test. Many people with intellectual disability are unable to work, either because of the severity of their disability, or more often, because there are so few opportunities for meaningful work. Parents of adult children with intellectual disability often make difficult decisions to limit their own employment opportunities because their children either need a great deal of care, or programs designed to care for their adult children have limited hours of support. In some cases, parents and guardians must also finance additional hours of care, sometimes in excess of their individual budgets as determined by the Department of Developmental Services (DDS). Parents who manage to acquire \$10,000 in assets have already made great sacrifices to provide care for their adult children. In many cases, parents are setting aside assets so that some resources are available for their children's care after the parents' death. Asking these parents to now have their already limited assets considered in determining their adult children's eligibility for Medicaid seems, as one parent noted "patently unfair."

We agree that in those cases where parents may have the resources to provide for their children's health care, they should partner with the State to share the costs of that care. We are concerned, however, that completely shifting the costs of healthcare to private healthcare plans does not take into consideration the special challenges faced by adult children with intellectual disability. Some private insurers specifically exclude any treatment for what those insurers still call "mental retardation." So many parents tell harrowing stories of wrangling with private insurers who may fail to distinguish between health care for their children that should be covered by the policy and refusing payment for services they consider treatment for "mental retardation". In addition, some employer-based group health insurance often have huge co-pays or deductibles (up to \$4000 for a family) that can be financially disastrous for families. The proposed cost shifting also assumes that some of the parents of adult children with intellectual disability may have jobs and health insurance. In fact, many of our parents work at jobs that pay the minimum wage and

either offer no health insurance benefits or the health insurance offered is simply unaffordable. So many parents of children with intellectual disability already have a financial burden taking care of their children. Forcing these parents to meet a new asset test will be a true hardship, placing an even greater burden on parents facing real challenges in caring for their children with intellectual disability.

We urge the Appropriations and Human Services committees to carefully consider the impact that imposing a \$10,000 asset test on parents of adult children with intellectual disability will have on parents and their families.

Thank you for your consideration.

Respectfully Submitted,

Andrea Barton Reeves

Vice President, Administration

HARC, Inc.