The Missouri Planning Council for Developmental Disabilities is gravely concerned over the multiple deaths of individuals with developmental disabilities that have recently occurred in Missouri’s large institutions. It is the Council's position that the state should aggressively investigate any incidence of abuse or neglect and ensure prosecution to the maximum extent of the law. Any suspected incident of abuse or neglect must immediately and thoroughly be investigated and reported to families, law enforcement, the public, and Missouri Protection and Advocacy Services, a federally-funded agency charged with investigating abuse and neglect of individuals with developmental disabilities.

Although an agreement between the Department of Mental Health, Division of Mental Retardation and Developmental Disabilities, and Missouri Protection and Advocacy was signed after a death at a habilitation center in 2004, prompt notification of incidents is still not consistently occurring. The Council feels it is critical that an independent agency receive immediate notification to allow a timely outside investigation to occur. It is also the position of the Council that a Department outside of Mental Health be established to take the lead in the review of abuse and neglect incidents and all investigations. No agency should be allowed to investigate itself. Any perception that these incidents are not thoroughly investigated by all parties responsible must be eliminated. We fear that a culture has evolved that shows too much tolerance and leniency for abusive behavior at habilitation centers and that this attitude has extended into local law enforcement and adjudicative systems. In addition, we feel it is vitally important that families, guardians, and advocates are allowed to visit their family member or individuals for whom they are responsible without prior notice.

The citizens of Missouri have entrusted the Department of Mental Health to provide quality care and to assist families in providing quality care for our most vulnerable citizens. The Council continues to urge the Department to develop an aggressive action plan to ensure the health and safety of individuals with developmental disabilities in our state. We continue to advocate that the input of families and advocates across the state is vital to the success of any plan developed.

The Council feels every effort should be made to support individuals and families in receiving services which will allow them to provide care for their family members in their home or a community setting of their choice. Recent research supports the fact that community settings result in improved quality of life in areas such as: Opportunities for integration and social participation, participation in employment, opportunities for choice-making and self-determination, quality and duration of services received, contact with friends and relatives, adaptive behavior, and other indicators of quality of life (AAMR, et al, 2004). The most recent research (Gardner, 2003) establishes the fact that there are no increased risks related to health and wellness, abuse, or safety when community affiliation, choice, and self-determination are increased. Large congregate settings have continued to prove to be unsuccessful in Missouri and the Council strongly recommends that the state accelerate its efforts to transition toward increased community options for all individuals with developmental disabilities.
The State of Missouri must work collectively to ensure that all individuals with developmental disabilities receive the services they need in an environment that will ensure they are free from abuse and neglect. It is unacceptable for individuals with developmental disabilities to live in any environment in which abuse or neglect is allowed to occur. The Council recognizes that a lack of adequate pay for direct care workers is a barrier to safe, quality support and that funding an increase for these workers should be a top priority. Training and credentialing of direct care professionals is also essential to ensuring quality of care. A pilot project, the College of Direct Support, is currently underway in our state to help achieve this very important step. It is important that we do not allow "SAFETY" to be used as a means to limit an individual’s right to choose a "life in the community." Quality of life is an essential component of "SAFETY" as well.

The Council and other Missouri advocates feel that the responsibility of protecting individuals with developmental disabilities is not only a legal responsibility but a moral responsibility, and we pledge to continue to seek resolution and assurances that the residents of all of Missouri habilitation centers, private ICF/MRs and community settings, are safe and have the right to a quality life.

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