

the national association of Developmental Disabilities Councils

September 8, 1999

Rodney Whitlock Legislative Director Representative Charlie Norword 1707 Longworth House Office Building Washington, DC 20515-1010

Dear Mr. Whitlock:

I am writing on behalf of the National Association of Developmental Disabilities Councils (NADDC), which represents State Developmental Disabilities Councils that work for change on behalf of people with developmental disabilities and their families. NADDC promotes national policy to enhance the quality of life for all people with developmental disabilities. NADDC supports H.R. 2723, the Bipartisan Consensus Managed Care Act of 1999. Thank you and Representative Norwood for your hard work on managed care patient protections and on this bill.

Children and adults with developmental and other disabilities and their families need protection in managed care. They often have extensive health care needs and high health related costs. Too often, managed care, in its effort to save money, does not provide them with adequate services. This can be disastrous for them.

H.R. 2723 provides an important opportunity to put aside partisanship and deal fairly with what the public has been calling for – new managed care consumer protections. Please, put aside party politics and help children and adults with disabilities and their families get access to health care they need. This bill would do a number of important things for people with developmental and other disabilities. It would help ensure that they have:

- Access to specialty care, including the opportunity to have a specialist as the
 gatekeeper or a standing referral for individuals with "ongoing special
 conditions". Ongoing special condition is defined as a "condition or disease
 that is life-threatening, degenerative, or disabling and requires specialized
 medical care over time";
- Continuity of care protections so that individuals with ongoing special conditions can continue to see their provider for a set period of time if, for some reason, the provider is no longer part of the plan;

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- Access to prescription drugs not in a plan's formulary if it is shown that a drug, other than those offered by the plan, is medically indicated;
- Access to an independent external appeals process that leaves decision making up to health care professionals and not insurance companies;
- Access to fair remedies if a health plan decision causes harm.

Again, thank you and Representative Norwood for your work on important issue of strong patient protections in managed care. Children and adults with developmental and other disabilities and their families need these protections if they are to live healthy and productive lives in the community.

Sincerely,

Mary Gennaro

Director of Federal-State Relations