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Statewide Parent Advocacy Network, Inc.

Family Voices comments on the CMS Proposed Guidelines on Rehabilitative Services

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We are writing on behalf of Family Voices-NJ concerning the proposed CMS Guidelines on Rehabilitative Services. Family Voices is a national network that speaks and advocates on behalf of children with special healthcare needs and our NJ Chapter is housed at the Statewide Parent Advocacy Network, NJ's federally funded Parent Training and Information Center. In addition, SPAN is the Family-to-Family Health Information Center for the state, and a chapter of the Federation of Families for Children's Mental Health. It is from these perspectives, the perspectives of the many families we assist, and our own experiences as parents of children and youth with special needs, that we are sharing these comments.

In *Overview / Section A*, the emphasis is that services "restore an individual to his previous functional level". How will this affect EPSDT (Early Periodic Screening Diagnostic and Treatment) and EI (early intervention) services for children? It further says that some states expanded "physical rehabilitative services to also include mental health and substance abuse" which is as it should be; states should be required to include mental health and substance abuse services. Rehabilitation is rehabilitation. There is also new awareness that mental illnesses can be biologically based and there should be parity in coverage for mental health with physical illnesses. Lastly, there is mention that "some States have used Medicaid to fund services that are included in...foster care and IDEA" and we feel this is as it should be as states are given flexibility in developing programs.

In the *Overview / Section B*, mention is made that some States have provided "day habilitation services...on behalf of persons with mental retardation". The suggestion is to use Medicaid waivers, which are difficult to obtain, and there is no uniformity among states. More importantly, Medicaid funding should go towards community-based, non-segregated settings. There should be a presumption, consistent with the U.S. Supreme Court decision in Olmstead, that services are going to be provided in community-based, non-segregated settings under virtually all circumstances!

Regarding *Section II Provisions of the Proposed Rule, Part B Scope of Services*, clarification is given on retaining the current definition of rehabilitation to include "maximum *reduction* of physical or mental disability" which would apply to early intervention and EPSDT; however it conflicts with the notion of "restoration of previous functional level" mentioned above for children who may not have attained skills yet because they haven't yet received necessary therapy. These discrepancies should be clarified so that it is clear that there is no requirement that children have achieved some previous functional level in order to be eligible for rehabilitation services.

Also in *Section II, Part C Written Rehabilitation Plan*, a suggestion is made that "covered rehabilitative services...must be identified under a written rehabilitation plan". How does this coordinate with a child's IFSP (Individualized Family Service Plan) or IEP (Individualized Education Program)? Statements are made that the benefit is "not custodial care for...chronic conditions but should result in a change of status." This is the same rationale that insurance companies use to deny nursing to a child; a child with a vent (ventilator) or trach (tracheotomy) doesn't need a babysitter, he needs a nurse. Also this contradicts the notion of "reduction of ...disability" mentioned above. Further statements support this in that "goals are contingent on the individual's maintenance of current level of functioning". Yet later in the document it states "services provided...to maintain...functioning in the absence of a rehabilitation goal are not rehabilitation services" with which we strongly disagree. We are very concerned about this statement because many children and adults with certain conditions may not necessarily improve but would certainly deteriorate without treatment and services. Suggestion is made that the rehabilitation plan be based on a "diagnosed condition" with which we again disagree as there is a range of abilities even within the same diagnosis justifying the need that "covered rehabilitative services for each *individual* must be identified" as stated previously. We do agree that anticipated outcomes are an essential component of the rehabilitation plan. We concur that flexibility such as including recreational activities to restore social functioning and personal interaction skills are a good example of implementation.

In *Section II, Part D Impairments to be Addressed*, we agree with state flexibility on determining rehabilitative services but feel that mental health and substance abuse should be required, as people with mental illnesses should have the same level of treatment and services as "physical" illnesses. We agree that looking at "assistive devices, supplies, and equipment" is necessary and would hope this includes medical supplies, such as those post-surgery, which would allow the individual to meet his/her rehabilitation goals.

Also in *Section II, Part E Settings*, we agree that services can be provided at a "facility, home, or other setting" which allows flexibility of natural environments. Skills learned in a clinical setting are not usually generalized to the natural environment so this will allow for better outcomes. To emphasize the importance of starting with homes and community settings, we recommend that the order be changed to "home, community setting, facility, or other setting."

Section II, Part F Requirements and Limitations for Rehabilitative Services #2 specifically eliminates or limits services previously provided. The overview stated this will "prevent coverage...that could be furnished through another program, such as... education". Many states have a Medicaid initiative to cover related services under IDEA (Individuals with Disabilities Education Act). This is up to and including nursing for children to allow FAPE (free appropriate public education) under IDEA. We're concerned about the proposal to limit transportation, personal care, vocational, and patient education; all of which are essential services for rehabilitation. We're also concerned about the lack of parity with mental health services proposing exclusions for "institutions for mental disease", including residential placements. Although it says states *can* use the "psych under 21 benefit for children", states have "flexibility" whether or not to have this, which is not likely to provide equitable access for persons with mental health needs. Lastly, the habilitative vs. rehabilitative argument defining the "capability to perform an activity in the past" will exclude therapies for children. How are children going to get the new ability without therapy? Section 441.45 rehabilitation services exclusions which include "non-medical support services...teacher aides" does not consider paraprofessionals who may provide related health services that aren't necessarily considered medical under special education law (e.g., special toileting, etc.) but are mandated. The proposal also limits therapeutic foster care, which is a concern.

Thank you for the opportunity to comment on the CMS proposed Guidelines on Rehabilitative Services and considering our concerns for this vulnerable population.

Sincerely,

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