

Meaningful Representation: Embracing “Nothing About Us Without Us”

The move to privatize Medicaid will affect the HCBS Waivers and will have a profound impact on access to healthcare for both families of children and youth with special health care needs and disabilities, as well as consumers themselves across their lifespans.

The motto “Nothing About Us Without Us” relies on a principle of equal partnership and participation first introduced to the world through the United Nation’s observance of empowerment for persons with disabilities in the 1970’s. It has since been used to achieve the full participation and equalization of opportunities for, by and with persons with disabilities worldwide.

Each MCO should construct a bid proposal that practices meaningful partnership with families and consumers:

- 1. Within your proposal for Value Plus Services, incorporate the use of natural family to family and peer to peer support services to provide access to real choice. “Natural supports” mean supports outside of systems, driven by families and individuals within our own community-based organizations.
 - a. Research suggests natural family to family and peer to peer supports assist in ways that keep crisis and costs within systems to a minimum. Many family and consumer run community-based organizations in Iowa train and match volunteer mentors with lived experience to families and individuals currently experiencing need. This type of natural support is a valuable resource that reduces the need for more costly services. This RFP affords an opportunity to utilize community-based, natural supports as a means of both empowerment and cost containment.****
- 2. The practice of equal partnership and participation through “Nothing About Us Without Us” also includes ensuring oversight committees, advisory councils, and other decision-making groups require 51% representation from families and consumers who are impacted by the decisions made. MCO’s**

**should incorporate this principle within their proposed bids,
and align with families and consumers to support this principle
within Iowa's new infrastructure for managed care.**

We deserve nothing less.