Testimony submitted to Joint Committee on Children, Families and Persons with Disabilities

June 25, 2019

**H.172 An Act relating to authorizing supported decision-making agreements for certain adults with disabilities**

This bill would authorize “Supported Decision Making” (SDM) in Massachusetts, an arrangement that would replace guardianships of persons with developmental disabilities in some instances with “networks” of more informal advisors.

The House bill (H.172) was filed by Representatives Aaron Vega and Paul Tucker. The Senate version of the same bill (S.64) was filed by Senator Joan Lovely.

Under SDM, individual guardians could be replaced by teams or “network supporters” who enter into written agreements with disabled individuals to help them make decisions about their care, finances, living arrangements and other areas. SDM proponents maintain that guardianship unduly restricts the rights of disabled individuals to make those decisions.

SDM appears to hold potential promise for some high-functioning individuals. The problem with the bill is that there appear to be few, if any, safeguards in it to prevent the potential marginalization of family members in decisions about the care of their loved ones with developmental disabilities. The bill also provides no standard for determining who might be eligible for an SDM arrangement.

What the bill does state explicitly is that under SDM, the developmentally disabled individual is the “decision maker” regarding their services and their financial and legal affairs. The bill skirts the question whether everyone is really capable of making their own decisions in those very important areas. What the bill needs to specify is a threshold level of cognitive ability above which SDM would be permissible and below which it wouldn’t.

There is also nothing in the language of the bill to prevent human services providers from being placed on the SDM teams — a situation that would seem to set up a potential conflict of interest.
More information can be found in our blog post at https://cofarblog.wordpress.com/2019/02/21/supported-decision-making-bill-needs-clarity-and-safeguards/

The following are changes to the language in H.172 that we have proposed to Representatives Paul Tucker and Aaron Vega, the principal sponsors of the legislation in the House. (Our proposed changes are in boldface below).

Under Section 1:

(g) "Supporter" means an adult who has entered into a supported decision-making agreement with a principal, provided that no employee of a nonprofit or for-profit organization providing, or intending to provide, services to a developmentally or intellectually disabled individual who is participating in a supported decision-making agreement shall be permitted to participate as a supporter in that or any other supported decision-making agreement involving that individual; provided also that no supporter shall be monetarily compensated for serving in that role.

Under Section 2:

(2) PURPOSE. The purposes of this section is to recognize that with support many people with disabilities can make their own decisions, to help such persons to exercise their human rights to make decisions, and to create a process which adults with disabilities who need assistance with decisions may choose to use to make and communicate decisions. Notwithstanding any other provision stated herein or in General Laws chapter 190B, supported decision-making shall not apply to any person with an intellectual disability or to a person with a developmental disability as defined in General Laws chapter 123B, section 1.