Most parents of young adults, with and without disabilities, are involved in their loved one’s life in many ways. This can include providing emotional support, advice, financial support, and sometimes room and board. Some young adults with intellectual disability and/or autism may also need support around making decisions. This decision-making support role may involve some legal steps as the person with a disability reaches the age of majority (age 18), to make sure family members can support their loved one in making important life decisions.

What approach works best to aid decision-making is different for each individual and family. Some individuals can make decisions without formal legal supports. For those who do need support, various options can be tailored to the individual’s needs. This makes it possible for the family members to provide assistance as needed, while still maximizing the independence of their loved one with a disability.

Decision-making supports can be tailored to specific life areas (such as health care or financial decisions) and to different levels of support that may be needed.

Figure 1 shows some of the options available here in Massachusetts. For definitions of each of these options, see www.dlc-ma.org/wp-content/uploads/2017/12/Alternatives-to-Guardianship-and-Guardianship.pdf.
Deciding what supports are needed should start with a discussion between the person with a disability and their family. Since it is easier to add more limits than to remove them, families may want to start with one of the options that offers more autonomy.

If you are unsure where to begin, it may help to talk to your family members, other families who are going through the same process, school personnel, your service coordinator from the Department of Developmental Services or counselor from the Massachusetts Rehabilitation Commission, or a lawyer with expertise in decision-making supports and guardianship.

Supported decision-making is a newer model for providing supports to adults with intellectual or developmental disabilities in their life decisions. In this approach, the individual keeps the ability (autonomy) to make decisions, while they receive assistance from a selected, trusted group of advisors to help them make these decisions. This arrangement, which can be formal or informal, is defined in a supported decision-making agreement. This approach may make use of other legal tools such as a health care proxy, power of attorney, and/or representative payee.

The Center for Public Representation, a legal advocacy center, has partnered with service provider agencies across Massachusetts to pilot supported decision-making. For more information and individual stories, visit supporteddecisions.org.

Resources for more information

Charting the Life Course Tool for Exploring Decision-Making Supports. This tool can be a useful starting point for discussing what types of decisions a young adult needs support with.  
www.lifecoursetools.com/download/tool-for-exploring-decision-making-supports/

Arc Position Statement on Autonomy, Decision-Making Supports, and Guardianship  
www.thearc.org/who-we-are/position-statements/rights/Autonomy-Decision-Making-Supports-and-Guardianship

LINK Center and Department of Elementary and Secondary Education Brochure on Decision-Making and Age of Majority  
https://fcsn.org/linkcenter/transition-resources/brochures/

Disability Law Center Publication for Self-Advocates on Alternatives to Guardianship  