

## SECTION 5: SECURING THE FUTURE: GUARDIANSHIP, SUPPORTED DECISION-MAKING, AND ‘KEEPERS OF THE DREAM’

This final section of the Letter of Intent invites the caregivers to take stock of their current situation and make plans for ‘who and how’ your hopes – and the hopes and dreams of your family member – will be heard and honored when you are not able to be fully engaged.

As caregivers, you can take steps now and make your intentions and hopes clear for the future. This section of the Letter of Intent, along with the conversation and information during Session Five of the Future is Now (FIN) series, can help outline hopes and plans for guardianship or supported decision-making, and naming – or building—a network of people who will look out for your family members best interest – the ‘keepers of the dream’.

### **Guardianship or Supported Decision-Making**

There’s no one decision that is right for everyone. The information provided in the FIN session will offer an opportunity to learn about guardianship and alternatives to guardianship. The handouts distributed during Session Five outline the differences between guardianship and supported decision making.

The National Guardianship Association has published a Position Paper that encourages family members and caregivers to “consider supported decision making (SDM) as an alternative to guardianship and as a decision-making paradigm within the framework of a nationally recognized best practices for assisting persons with cognitive disabilities.” The paper goes on to outline the definition of supported decision making:

*...where people use trusted friends, family members, and professionals to help them understand the situations and choices they face, so that they may make their own decisions... where an individual with cognitive challenges is the ultimate decision maker, but is provided support from one of more persons who explain issues to the individual and where necessary, interpret the individual’s words and behavior to determine his or her goals and preferences. Guardianship should be utilized only when lesser restrictive supports are not available.*

Even under existing guardianship, the guardian can still use the principles of supported decision-making as a way to engage trusted friends and allies in helping the person understand a situation and make choices.

Use the space below to record some things you hope that friends and allies of your family member will remember or do in order to help your family member be engaged and supported when decisions need to be made about his/her life. If your family member does not use language/words to communicate, you might record ideas about what to watch for, or how your family member communicates in other ways besides words.

How my family member can be supported and heard and engaged when decisions need to be made:

Family members and caregivers can contact Disability Rights Ohio for more information and assistance with guardianship and supported decision-making. They have created a power point which can be viewed here:

<file:///C:/Users/Owner/Documents/FIN%20Family%20Sessions/Supported%20Decision%20MakingPPT.pdf>

### The Keeper of the Dreams

Look back at the “Hope and Dreams for a Good Life” that you created in Section One. The “Keeper of the Dream” is the person – or group of people – who keep these hopes and dreams alive when you are not able to do so. It’s important to remember that the “keeper of the dream” is not necessarily the person/s that provides day-to-day care for your family member. The Keeper of the Dream looks out for, advocates, and takes your family member’s life seriously. They guard against the ‘things we don’t want’.



1. Look back on Section One at the “Hopes and Worries” worksheet that you completed. Take time to add to it if you’ve had new ideas about hopes or worries. Take some time to reflect on what it would mean for someone (or some people) to be the keeper of your family member’s dream. It means different things to different families. Do you want the person to check in on your family member on a regular basis? Speak up if they see things that are out of line? Be alerted if the person has an emergency? Record your ideas here:

2. Review your hopes and plans for building your family member’s network of friends and allies. Is there someone – or a group of people -- you can ask to be the keeper?

3. Remember that building a network takes time, and if your family member’s network is small now, and there’s no one to ask, then you can start now to intentionally build up your family member’s network. There are resources in the Greater Cincinnati area, such as Good Life Network [goodlifecincy.org](http://goodlifecincy.org) that help families build networks. Use the space below to name the first steps you can take now so that in five years, you are able to identify ‘the keeper of the dream’.



### Where Do We Go From Here?

- **COMPLETE THE LETTER OF INTENT:** Continue to work on your Letter of Intent. Complete the sections that are most relevant for your situation. Share it with your family and friends. Share it with your Service and Support Administrator (SSA) and attorney if you have one.
- **INVEST IN DEVELOPING A PERSONAL NETWORK:** Continue to build up a network of people who know and care for your family member. Get help doing this by attending Good Life Network Community Conversations. See the Good Life Network brochure and/or check the web site at [goodlifecincy.org](http://goodlifecincy.org)
- **ENCOURAGE CONNECTIONS:** Help your family member get more engaged with his/her community by joining Neighbors in Action. For more information contact Ann Myres or Dawn Freudenberg ([ann.myres@hamiltondds.org](mailto:ann.myres@hamiltondds.org) , [dawn.freudenberg@hamiltondds.org](mailto:dawn.freudenberg@hamiltondds.org))
- **STAY CONNECTED:** Join an existing Caregiver Resource Group hosted by Caregiver Assistance Network (CAN). See flyer.
- **COME TO A RE-UNION:** We will hosting a re-union of Future Is Now families. Over time, we'll build up a network of families who can convene and re-connect.
- **CONTACT US:** Stay in touch. We welcome your questions and updates. (Dawn Freudenberg and Jo Krippenstapel [dawn.freudenberg@hamiltondds.org](mailto:dawn.freudenberg@hamiltondds.org) and [Jokripp@cs.com](mailto:Jokripp@cs.com))