

Families Preparing for Family Care 2.0¹

Dane County families of people with Developmental Disabilities face a major shift in the way supports are managed. There are many uncertainties about the details of implementation, but it is not too soon for families to begin preparing. In response to the Legislature, the Department of Health has outlined a plan to bring primary and acute healthcare and long term care for frail elders, people with physical and sensory disabilities and people with developmental disabilities under integrated management.² Some important changes include:

- Dane County will no longer contract for, manage or coordinate DD services for adults. An IHA (Integrated Health Agency operated by an insurance company supervised by the Commissioner of Insurance rather than the Department of Health) will manage these functions for a zone that includes about a third of Wisconsin's counties. Service coordination by the IHA will replace Dane County brokers. Services to citizens of Dane County will be managed along with all the residents of ±20 other counties who need long-term care: frail elders, people with physical and sensory disabilities, and people with DD.
- The same IHA will coordinate all of a person's primary and acute health care as well as long-term care.
- People with DD or their guardians will have a choice among three insurance companies to provide their health and long-term care. They can also choose to self-direct their long-term care.
- Current transportation arrangements with Madison Metro will be lost unless a way to preserve them is found.

Concerns

Most family members present feel that this change has just appeared as an unwelcome surprise without their involvement. There may have been family members involved in the process, but, if so, it

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- WI Long-Term Care Coalition www.wilongtermcarecoalition.org
- Save IRIS www.saveiris.org
- The Arc of WI www.arc-wisconsin.org
- Dane County DD Coalition www.facebook.com/ddcoalitionofdanecountyinc
- LoV Dane www.lovdane.org

¹ These notes summarize key points from three discussions among family members interesting in learning more about the changes coming to Dane County, facilitated by Lynn Breedlove and John O'Brien on 3 May 2016. Each discussion was different in parts and each family member spoke for themselves. Similar points are grouped together in this note.

² A summary of what is now known about Family Care 2.0 by Lynn Breedlove is attached.

happened in a way that neither included nor informed them. They have not been consulted so far and if they could reverse the change, they would. A number want to make the most of whatever opportunities remain to have a say in the development and implementation of the process. They would welcome updated information and connections to others working to have a positive influence. They want to know where these ideas came from and what the evidence and experience in other states is to support them. (The box above provides web links that will help with this. Family Care 2.0 is also regularly covered in the media – www.wilongtermcarecoalition.org provides links to media coverage across Wisconsin. A sense of how a similar approach is working in a nearby state can be found in occasional stories available on the *DesMoines Register* website.)

The current system has many imperfections but it offers almost everyone support for a good quality life most of the time and its managers and providers have kept up efforts to improve for more than 40 years. The system is local and accountable to local elected officials. Some parents have trusted the system to play a significant part in answering the question, “Who can I trust with my son or daughter’s life when I am no longer able to?” The shift from being citizens supported by locally accountable people to being customers expected to seek the best deal from competing, large insurance companies is a big and disturbing one for some family members.

Many family members value their relationship with their brokers and count on them for a variety of kinds of assistance, from managing paperwork to carrying knowledge of and standing up for what is most important in the person’s life. Brokers have personal relationships which have often lasted for years. They are involved in people’s lives and regularly in touch. Families want to maintain the personal connection that supports them. Having service coordinators work at a greater organizational –if not geographic– distance than brokers do now sacrifices a great deal. In the current system brokers are part of a negotiation process to determine individual budgets and manage unusual costs. If IHA service coordinators are tied to standardized templates and protocols (as is common in the insurance industry), there will be a significant loss in flexibility.

Some families see a big difference between managing long-term support and managing the costs of primary and acute health care. Long-term support immediately affects everyday life, every day through the whole lifespan. There is a risk that medical model thinking and practices will spill over into IHAs approach to long term support. This will dilute the values on support for citizenship and community participation that have built good supports.

Many family members see caring, personal relationships as fundamental to their family member’s well being. They are concerned that a numbers game will have more weight in decision making than care for people does.

Many family members are satisfied with their provider organizations and with the relationships they and their family members have with provider staff. Some of these relationships are

decades long. Dane County has encouraged local providers, including a number of small organizations. IHAs might favor bigger organizations that work state or nation wide. IHAs might also push to shift people to providers that promise lower costs. This would mean more transitions that disrupt people's lives.

Given the shortage of direct support workers, each group wondered how IHAs will pay them and assure adequate funds for their training and supervision. They are concerned that IHSs will not respect Dane County's Living Wage Policy, making the scarcity worse. They want to know what affirmative steps IHAs will take to improve the supply and retention of skilled direct support workers.

Some family members are aware of the very large disparity in numbers employed in Dane County and those employed under the management of current Family Care organizations (3 to 5 times more people with DD have community jobs in Dane County). They value their family member's job and want to be sure that IHAs pull other counties up rather than dragging Dane County's employment rate down.

Some families are aware that Dane County supports many more people to live in person-scale supported living arrangements outside the family home than other areas of Wisconsin do. They are concerned that IHAs might be slower to offer people the opportunity to move out of their family home. Some also think that IHAs might assume that bigger group living arrangements are cheaper and pull people into bigger groups. IHAs might even come up with a modern form of institution, gathering unusually large numbers of people under one roof maybe with the rationale that the facility will provide specialized services.

Some family members are skeptical of the idea that for-profit IHAs can find enough effective measures to economize to avoid using their position to push rates and the quality of support down. They believe it likely that profit seeking will compromise quality. The fact that costs of acute health care are also an IHA responsibility increases their concern.

Some people with DD have complex medical conditions that are managed by sustained relationships with health care providers from different provider networks. It is essential that IHAs make it easy to preserve these hard won relationships. There are also questions of how resilient IHAs will be to paying for very high cost medical conditions, including questions about provision for adequate re-insurance.

Some people with DD have complex behavioral health issues. Support from TIES has been critical to their wellbeing and the collaborative relationships TIES staff have established with people, families and provider staff need to be preserved.

The loss of current transportation arrangements would impose significant limits on many people's lives.

In recent implementations of Family Care, County staff have been forbidden by the Department of Health to communicate with citizens about matters related to the change. It is uncertain

whether this policy will carry over to the implementation of Family Care 2.0 but it encourages families to find or develop independent sources of information and be active in sharing what they know.

Moving Forward

Thinking about such big changes –imposed without consultation on people with DD, families, service providers, and local government officials who have worked hard for a generation to build supports that people can count on– can be a source of fear and anger that leads to cynicism, discouragement and resignation. The future for people with DD depends now, as it always has, on people who resist discouragement and work together to find the best way forward. Withdrawing to wait and see what the new system will give separate individuals won't make a difference to what comes. Neither will trying to get as much as possible for one's own family member without regard for everyone else affected by the change. What will make a difference is being as active as possible in alliance with as many people as possible to use as many channels as possible to influence what happens and respond to make the best of whatever the changes are.

Everyone can take responsibility for staying informed by using the web links and taking opportunities to get together with others. There are already efforts to learn from families in current Family Care areas (contact stefanie@lovdane.org) Everyone can take responsibility for making sure that extended family and friends know about the changes and what they can do to help. As things unfold family members can decide what do to make best of what comes for everyone, including those people whose families are unable to be an active support. There are a range of opportunities for action from letter writing and offering testimony to actively participating in and organizing group efforts to support positive action for individuals and for the whole community.

In addition to influencing Family Care 2.0, there is an important local conversation to have. For decades Dane County has chosen to make additional investment in support to its citizens with DD and their families. Family Care 2.0 reduces local investment in Medicaid funded long-term care each year for five years. This raises the question, ***Once Family Care has taken over responsibility for managing a network of adult service providers, how will Dane County government invest in adult citizens with DD?*** Finding a resolution to the potential loss of transportation funding is an urgent community issue. This might make a good place to focus the local conversation now.

Family Care 2.0 provides an option for people or guardians to choose self-direction. While important details are uncertain, it will surely be different from the approach to self-direction Dane County has pursued since the mid-1990s. As many families as possible should keep themselves informed and consider the self-direction option as the best way to preserve and

build on what is most important. Families could join together to organize and make the best of what emerges from Family Care 2.0.