Some Lessons From Seven Supported Decision Making Pilot Projects

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Some Details About the Center for Public Representation

- The Center for Public Representation https://centerforpublicrep.org has been a leading national legal advocacy center in the United States for over forty years.
- As it says in their mission statement "the Center uses legal strategies, advocacy, and policy to promote the integration and full community participation of people with disabilities and all others who are devalued in today's society.
- The work of the Center is done in cooperation with many allies throughout the US and abroad

Some Details About the Center for Public Representation

- The Center for Public Representation is the overall host of six of these pilot projects in the state of Massachusetts.
- It has partnered with five Massachusetts non governmental community service organizations to launch and maintain efforts to keep the pilot projects going
- Its supported decision making (SDM)work is lead by a small staff team under the title of the CPR "Supported Decision Making (SDM) Initiatives"
- It is now updating its SDM website www.supporteddecisions.org

Some Details About the Center for Public Representation

- The work of the Center on supported decision making extends beyond the pilot projects to training, technical assistance, materials development and other collaborations
- A current area of special focus has been supported decision making in the medical care context
- Also of importance is the Center's efforts to reach out to involve persons and families from cultural and linguistic minorities with SDM

Some Details About the Center for Public Representation

- Another recent SDM initiative of CPR has been to partner with a diversity of other organizations in Massachusetts to seek passage of a Massachusetts supported decision making bill already filed by this coalition in both houses of the Massachusetts legislature
- Like other groups CPR has emphasized the use of supported decision making as being the preferred and least restrictive place to begin when supporting people in lieu of beginning with guardianship

Some Details About The Seven Pilot Projects

- Six are in the state of Massachusetts and the seventh one is in the state of Georgia.
- Six of these pilot projects have been funded thus far by private grants from charitable foundations within Massachusetts and nationally in the US
- The partner organizations are providing support to the projects by donating the time of their staff that is dedicated to their project.

Some Details About The Seven Pilot Projects

The five Massachusetts supported decision making partnering organizations with CPR are:

- Nonotuck Resource Associates (2 pilot projects) https://www.nonotuck.com
- Massachusetts Families Organizing for Change https://mfofc.org/about/
- Northeast ARC https://ne-arc.org

Some Details About The Seven Pilot Projects

- Advocates https://www.advocates.org
- Multi Cultural Community Services https://www.mcsnet.org

Some Lessons From Seven Supported Decision Making Pilot Projects: Feasibility

- These projects are small in terms of the number of participants & have only been in place for a few years and so one must be cautious about concluding too much too soon.
- Nonetheless, engaging a variety of interested people with SDM practice has proven to be feasible, as has been enlisting organizational support as exemplified by the number of supporting organizations.

Some Lessons From Seven Supported Decision Making Pilot Projects

- The initial exploration of SDM may not be the same as what might be gained with long term practice, so the experience in Massachusetts and Georgia is necessarily short term in nature
- By comparison, there are jurisdictions, such as in various western Canadian provinces, who have had decades of experience with SDM type practice

Some Lessons From Seven Supported Decision Making Pilot Projects

- Thus far, our pilot project experiences appear to largely mirror that of others in that SDM is increasingly of genuine interest to many people and some are deciding to practice it if the opportunity is available.
- Ongoing SDM practice has been initiated and maintained with persons with a wide variety of ages, disabilities and personal life circumstances

Some Lessons From Seven Supported Decision Making Pilot Projects

- It would appear that the use of SDM, *in combination with* health care proxies, durable power of attorney, representative payee and similar measures, has *thus far* made guardianship unappealing and unnecessary for existing project participants i.e. none have elected for guardianship in preference to SDM
- Most participants were largely unaware of both SDM and these other options that can be combined with SDM until their engagement in the pilot projects

Some Lessons From Seven Supported Decision Making Pilot Projects

- SDM may likely have been more consciously embraced by participants as a preferred alternative to guardianship given the character of the various pilot project's "pro SDM" orientation, trainings, recruitment and other positive supports
- Most people in the projects had been urged on occasion by others (prior to exposure to SDM) to take up guardianship and might conceivably have eventually done so prior to hearing about SDM i.e. ongoing SDM involvement seems to have built confidence that guardianship is not needed.

Some Lessons From Seven Supported Decision Making Pilot Projects

- A small number of SDM participants and their families with guardianship already in place have either explored or successfully obtained the termination of pre existing guardianships
- The SDM experience has *at least thus far* given participants confidence that guardianship is not needed, as none of the pilot project participants have so far considered applying for guardianship

Some Lessons From Seven Supported Decision Making Pilot Projects

- The existence of ongoing SDM pilot projects has been very facilitative of people getting the education, support and alliances that help get them started and continue with SDM
- It is not clear yet whether these participants would persevere with supported decision making without either specific pilot project supports or possibly some other similar support

Some Lessons From Seven Supported Decision Making Pilot Projects

- SDM has thus far been introduced to, explored and used on an ongoing basis by persons from minority linguistic and cultural groups i.e. Latino, Russian, Vietnamese, Ukrainian etc.
- In each instance, supporters from within those cultures have been sought, obtained and retained, albeit in small numbers.
- Even so, the pool of such examples is still relatively small in size (approximately a third of all project participants)

Some Lessons From Seven Supported Decision Making Pilot Projects

- Many families and others involved often struggle with how to find supporters on their own or are fearful that they may fail to find suitable people
- It is not initially clear to most people what might be involved in sustaining ongoing SDM practice
- Getting people started and persisting with SDM is decidedly helped by being part of a specific SDM project and an extended SDM network

Some Lessons From Seven Supported Decision Making Pilot Projects

- It is easy for many people initially attempting to undertake SDM to get "stuck" with how to proceed and they may stay that way unless they get some specifically targeted instrumental and emotional support in a timely way
- Proactive intervention is helpful, whereas letting people struggle without progress is discouraging for them

Some Lessons From Seven Supported Decision Making Pilot Projects

- Supported decision making is not solely about decision making so much as it is about engaging the life experiences and substantive challenges the person is encountering at a given moment that will require decisions by the person
- All life challenges are typically easier to manage with support and SDM can be one source of that support, but it can also be coupled with other forms of both formal and "natural"support.

Some Lessons From Seven Supported Decision Making Pilot Projects

- SDM is inherently a personal developmental process for those involved and thus will require ongoing proactive initiative from participants and supporters to both keep it going and to further evolve its practice
- It is driven by the initiative, commitment and interest of those directly involved plus the positive catalyst influences brought by committed external supporters such as pilot projects

Some Lessons From Seven Supported Decision Making Pilot Projects

- The use of formal "supported decision making agreements" has ben helpful for clarifying the roles of supporters and selection by the person of the specific supporters they prefer for given areas of their decision making
- However, their use would in many instances need to be encouraged, as these are not familiar or "natural" to most people and thus some people may need persuading to try them out.
- Typically, the signing of these agreements has included a ceremony that has brought about added meaning and significance for those present

Some Lessons From Seven Supported Decision Making Pilot Projects

- The presence of SDM training, mentoring and other learning opportunities are a significant advantage, as these supports serve to develop clearer understandings of what SDM is as well as potentially provide an organized way to get questions answered promptly
- SDM training and other support options are not currently standardized, nor have these been systematically evaluated for impact and value over time leaving us only with anecdotal insights

Some Lessons From Seven Supported Decision Making Pilot Projects

- Citizen Advocacy and supported decision making are quite consonant with each other in many ways and it is too early in the process of bringing them together to know precisely how well they could optimally fit together
- Fortunately, the means and tradition of doing this exploration thoughtfully are present in Georgia
- Nonetheless, a plan to guide this reflective process will need to be created

Some Lessons From Seven Supported Decision Making Pilot Projects

- Supported decision making practice typically has strengthened the presence of supporters in the focus person's life in an overall way
- Though there is scope for increased numbers of supporters in all of the pilot projects, the key may be more the quality of the supporters that are available at a given time and their reliability rather than solely greater numbers of them.
- People have initially turned to persons with whom they already have a relationship to be supporters