

This document summarizes the feedback received from 14 groups of workshop participants on two presentations made by collaborating groups of service providers. Workshop participants included individuals with developmental disabilities, family members, and representatives from service providing agencies.

## **Hillside Family of Agencies: Hillside Family Finding, Creating Lifetime Networks**

### **Aspects Workshop Participants Liked Best**

- *Loved the way the video was used to introduce/communicate with individuals and family members.*
- *Wonderful and creative example of using natural support of family and friends to build a stronger circle of support and improve the overall quality of each individual's life.*
- *Interesting and informative example of how one agency recognizes core loneliness and sees the richness of relationships a person can have.*
- *The movement to encourage family members to become involved in the lives of their relatives with developmental disabilities.*
- *An excellent tool for (re)connecting the individuals involved and decreasing the costs associated with supporting individuals.*
- *Special focus on person centered natural supports is ideal for individuals.*
- *Relationships are important and everyone needs to have someone stable in their lives ~~who that~~ is not paid to provide care.*
- *Embracing natural supports is a very innovative concept.*
- *Believing that people generally function better with family and the dedication to helping people find loved ones is an outstanding concept.*
- *Possible decrease in maladaptive behaviors.*
- *Emphasis on moving individuals out of certified sites and into family placements is the wave of the future.*
- *Despite the end result of possible broken families, no reason not to try.*
- *Encouraged by the idea that everyone has potentially 100-300 relatives.*
- *The project undoes the tragedy of segregation from the community. Ironic that funding for this project is needed to undo the historic placement of people from their homes and the perhaps well-meaning but continuing efforts of staff in group placements to separate individuals from their families.*

### **Aspects Participants felt would be a Challenge to Implement**

- *Too costly, labor intensive and time-consuming in terms of staff and resources needed to find family members and connect/implement effectively, especially once start-up grant funding runs out.*
- *It may be more difficult to engage family in the lives of individuals who are more physically or behaviorally challenged and/or have severe needs. Also family members that are spread out over a large geographic area may be problematic.*
- *Many individuals come from dysfunctional/distant families – it is hard to believe that due to this initiative, these relationships will be unconditional or lasting. A father who abandoned a child at age 7 cannot necessarily be dependable moving forward.*
- *Must be careful not to elevate expectations too much for individuals that their family members will actually spend a significant amount of time with them. This could have a very negative impact on individual psyche. The potential for a second “abandonment” must be monitored very carefully.*
- *Although this is a model with a proven track record, there should always be significant oversight, especially in the early going, and a continuous safety plan. Oversight is key.*

<ul style="list-style-type: none"> <li>▪ Ensuring that individuals and “found” family members have ongoing, consistent support and commitment to remain in one another’s lives might be difficult.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Helping individuals, especially older ones, “buy in” to the family finding concept, especially if they think they <i>ye</i> have no family out there. Also might be harder to find their relatives.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Lack of corroborating family information in agency records.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Safety concerns for individuals when they are around family members who essentially are strangers.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Clear expectations of what families can do for individuals.</li> </ul>
<ul style="list-style-type: none"> <li>▪ What happens when a reconnected family member “drops out” of an individual’s life? It may be unrealistic to expect them to remain connected over the long haul.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Program is based on the premise that family relationships will be positive.</li> </ul>
<ul style="list-style-type: none"> <li>▪ The agency might not necessarily know each individual’s “back story” going into the family finding process – there might be a valid reason, such as neglect or abuse, why there is no family involvement.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Even intact families become estranged/less involved over time – how do you plan for this outcome?</li> </ul>
<ul style="list-style-type: none"> <li>▪ Managing family dysfunction.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Appears to be a staff-intensive attempt to reduce OPWDD costs and have families (who are likely struggling financially to stay afloat) replace staff expenses.</li> </ul>
<p><b>General Concerns Noted</b></p>
<ul style="list-style-type: none"> <li>▪ Offended when the presenter inferred that individuals could (or every effort should be made to) live with or connect with family member. Felt that the agency was searching for relatives to personally “guilt” them into a relationship with individuals.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Did not understand why this presentation was included – thought the purpose of Innovative Ideas workshops was to inform stakeholders of organizations that want to become DISCOs and how they plan to organize themselves.</li> </ul>
<p><b>Promising Aspects for Local Innovation</b></p>
<ul style="list-style-type: none"> <li>▪ Model could be adopted by any agency.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Increasing family involvement by finding relatives who are willing to make an unconditional lifelong commitment has potential to offset a reduction in paid services.</li> </ul>
<ul style="list-style-type: none"> <li>▪ If funding was available, it would be an excellent service to provide, especially for those who were under the impression they have no family.</li> </ul>
<ul style="list-style-type: none"> <li>▪ A pilot project to address those with more severe needs to see if their family members step up to the plate.</li> </ul>
<ul style="list-style-type: none"> <li>▪ All individuals should have a “family finding” completed before the needs assessment is concluded. Then a person-centered plan could be developed which is implemented by the care coordination team.</li> </ul>
<ul style="list-style-type: none"> <li>▪ As an MSC, having close to 50 individuals in my caseload, most of whom have very little family involvement, it should be mandated for them to receive “family finding” (if they choose and are able to choose). It would definitely enhance the quality of life of each person.</li> </ul>
<ul style="list-style-type: none"> <li>▪ For individuals who have the need for family connections, “Family Finding” lifetime networks can be helpful in supporting their needs.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Using a computer-generated record <i>ing</i> mining search to locate families and obtaining the resources necessary to assist in family searches is an excellent element that would aid family finding agencies in their efforts.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Focus on strengthening existing family relationships for individuals with already-identified family connections.</li> </ul>

▪ <i>Appears that the Family Finding concept will work best with higher functioning individuals.</i>
▪ <i>Working with habilitation plan writers to build family connections (and in some cases replace paid professionals where possible) will improve measurement of valued outcomes.</i>
▪ <i>Training staff to use the valuable family finding asset will play a pivotal role in creating a stronger family network.</i>
▪ <i>Using technology to connect individuals and their family members is a low-cost tool with potentially huge payoffs.</i>
▪ <i>Importan<del>cent</del> of identifying one main family point person as the primary contact.</i>
▪ <i>Family networking can increase potential for employment outcomes.</i>

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# **NYSARC: Statewide Coordinated Care Program for Persons with Developmental Disabilities**

## **Aspects Workshop Participants Liked Best**

- *Great to have a structure started, especially if there is a dedicated team of individuals working on the individual pieces. Plan was well-researched and had depth.*
- *Presentation was very clear, concise and informative, especially in breaking down the interpretation of what a managed care organization (MCO) looks like.*
- *A good example of what a statewide association can do for its members to maintain chapters' individual identities while building a strong network.*
- *A well thought out plan and tremendous network/organizational structure with staff and financial resources to get it off the ground.*
- *Person-centered principles and uniform quality standards.*
- *Consolidation of ARC chapters – culture, systems, financials, etc. Emphasis on partnerships.*
- *NYSARC seems very well positioned to provide a single statewide coordinated system of care and services, especially in underserved and rural areas.*
- *Explanation of how the seven regional management services organizations (MSO) will eventually make the chapters more efficient with standardized work flow and back office opportunities.*
- *The presentation cast NYARC in a proactive light, especially its capacity to take on risk.*
- *Liked the structure of the MCO, especially the consolidation of management positions.*
- *Moving away from fee-for-service options.*

## **Aspects Participants felt would be a Challenge to Implement**

- *Putting all of this in place looks like a daunting task. Still talking in generalities rather than specifics.*
- *Health care under managed care for individuals with developmental disabilities.*
- *Education of parents or family members as well as addressing any concerns they may have.*
- *Difficult to provide individualized plans when providing only one entity the responsibility for ensuring that each person's full range of needs are met.*
- *Managed care does not cover many services that OPWDD consumers need.*
- *Getting needed agencies/resources on board and willing to take on risks.*
- *Moving the habilitative model into managed care on such a large scale.*
- *Parents keep hearing about supports to help keep individuals living with their families. What about families who do not want that option?*
- *Although NYSARC spoke about reduced redundancy, shared services and improved efficiencies, the model seemed very bureaucratic with seven MSOs, the DISCO/MCO, parent groups and OPWDD. Isn't this the opposite of efficient with all of the administrative costs?*
- *Seems like a conflict of interest in terms of "the fox guarding the hen house" (i.e., nonprofit governing another nonprofit rather than the State doing so).*
- *NYSARC's MCO does not seem very different from OPWDD itself -- how would it offer something more personal than what OPWDD already provides? Why can't some of the suggested elements be implemented now (i.e., group purchasing, innovations, etc.)*
- *Difficult to implement care coordination model, especially in light of financial risks.*
- *Why are the MCO regions different than the OPWDD regions?*
- *Standards can be a problem if they don't take into consideration regional differences in cost.*

<ul style="list-style-type: none"> <li>▪ <i>Obtaining full family involvement might be challenging.</i></li> </ul>
<ul style="list-style-type: none"> <li>▪ <i>Smacks of re-institutionalization – NYSARC is “married” to congregate/segregated care model. It will be difficult to change.</i></li> </ul>
<ul style="list-style-type: none"> <li>▪ <i>Difficult to manage care coordination with agencies that aren’t part of the MCO as well as difficulty coordinating acute care services.</i></li> </ul>
<ul style="list-style-type: none"> <li>▪ <i>Concerned about the levels of administration and “contracting out.” This will significantly decrease funding for direct support staff.</i></li> </ul>
<ul style="list-style-type: none"> <li>▪ <i>Self-directed services within a DISCO/MCO will be a huge challenge.</i></li> </ul>
<ul style="list-style-type: none"> <li>▪ <i>Lack of specificity for individuals with significant needs in a managed care world.</i></li> </ul>
<ul style="list-style-type: none"> <li>▪ <i>Difficulty for real involvement by individuals, families and advocates in the entire process from inception and throughout given the size of the MCO.</i></li> </ul>
<ul style="list-style-type: none"> <li>▪ <i>Lack of health care experience and rising health care costs are a bit part of the problem.</i></li> </ul>
<p><b>General Concerns Noted</b></p>
<ul style="list-style-type: none"> <li>▪ <i>Did not feel this was the right forum for the NYSARC presentation. It gave an overall presentation on the new structure under the new Waiver, but did not tell parents what innovative ideas will make the individuals’ lives better.</i></li> </ul>
<ul style="list-style-type: none"> <li>▪ <i>One agency was concerned that its successful model for employment opportunities does not appear to be part of the employment conversation. It felt much could be learned from its experiences to date, but its uniqueness may preclude it from fitting into a managed care model.</i></li> </ul>
<ul style="list-style-type: none"> <li>▪ <i>Although many voluntary agencies liked the NYSARC concept of consolidation and standardization, they had a hard time understanding how they could possibly fit into the NYSARC model due to their size and/or specialty. The Waiver Liaison’s recommendation to consider joining together with similar size agencies was not well received.</i></li> </ul>
<ul style="list-style-type: none"> <li>▪ <i>Would have liked more information about care coordination.</i></li> </ul>
<p><b>Promising Aspects for Local Innovation</b></p>
<ul style="list-style-type: none"> <li>▪ <i>Maintaining the habilitative model within managed care is important.</i></li> </ul>
<ul style="list-style-type: none"> <li>▪ <i>Collaboration of services and local agencies will better position regions for transition to the People First Waiver and managed care.</i></li> </ul>
<ul style="list-style-type: none"> <li>▪ <i>The reduction of redundant services looks like an area for potential innovation.</i></li> </ul>
<ul style="list-style-type: none"> <li>▪ <i>Much will be learned in the pilot phase.</i></li> </ul>
<ul style="list-style-type: none"> <li>▪ <i>Multiple agency involvement makes it more likely that new ideas can be implemented.</i></li> </ul>
<ul style="list-style-type: none"> <li>▪ <i>The coordination of back office functions (business approach vs. human services approach) seems like it could work well in an area with many small agencies. Group purchasing and reducing administrative redundancies will have important implications.</i></li> </ul>
<ul style="list-style-type: none"> <li>▪ <i>Increased capacity to meet individuals’ unmet needs in a managed care system.</i></li> </ul>
<ul style="list-style-type: none"> <li>▪ <i>When considering care coordination, NYSARC should look to the NYS Office of Children and Family Services’ “Bridge to Health” (B2H) model that uses a care coordination function for children in foster care. These children fall into three categories: medically frail; developmentally disabled; and social/emotional needs.</i></li> </ul>
<ul style="list-style-type: none"> <li>▪ <i>Encourage more partnerships among existing agencies.</i></li> </ul>
<ul style="list-style-type: none"> <li>▪ <i>Excited about the local Region 3 NYSARC chapters which have already been implementing an MSO creating standardization and efficiencies. Most of the agencies in the North Country are used to working together and this concept should make it easier.</i></li> </ul>

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| ▪ <i>The flexibility of managed care and potential for service enhancement was viewed in a positive light.</i>                      |
| ▪ <i>Less costly than the State running things.</i>   |
| ▪ <i>Nassau FIDA is already well developed along these lines.</i>   |
| ▪ <i>Potential for regional service provider ARC chapters to share information technology and human resources responsibilities.</i> |

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