



Sibling Needs Assessment

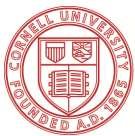
Executive Summary and Recommendations

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Introduction

Societal successes in improving medical and social environments for individuals with developmental disabilities have led to their leading increasingly full and long lives. As a result, many siblings may find themselves assuming a primary contact role for their brother or sister with a disability as their parents age. There is limited research on the needs of adult siblings of persons with disabilities and no recent studies have focused on this population in New York State. The New York State (NYS) Developmental Disabilities Planning Council (DDPC), in their efforts to identify and assist adult siblings of NYS residents with developmental disabilities, funded the Employment and Disability Institute (EDI), in collaboration with The Advocacy Center (TAC), to conduct a needs assessment. The NYS Sibling Needs Assessment project began November, 2011 and concluded in June of 2013.

This DDPC-sponsored project included the development, implementation, and analysis of two surveys:

- (1) The *Service Delivery Survey* measured the current level of supports and services offered to siblings in NYS by the OPWDD-funded service delivery system and
- (2) The *Sibling Survey* assessed the current state and needs of adult siblings regarding knowledge, training needs and care capacity for their sibling with developmental disabilities.

Based on findings of the needs assessment surveys and two follow-up focus group discussions with agency representatives and siblings, we offer a set of recommendation and a logic model for implementation of activities and programming for agencies and siblings. An additional project output was the creation of a database of self-reported adult siblings of NYS persons with developmental disabilities for future outreach efforts.

The full project report contains a complete description of the project methodology, recommendations with supporting data, and a table of current sibling initiatives active nationally and in NYS. In this executive summary, we provide recommendations for program planning based on our needs assessment, beginning with a recommendation for developing a strategic plan and then focusing on recommendations around identifying siblings, agency training on sibling issues and reaching siblings, and sibling/family training and outreach that we believe should be incorporated into that strategic plan.

Overarching Recommendation: Develop a strategic implementation plan for sibling initiatives.

Utilize this report, logic model, and recommendations as a basis to develop a strategic plan for increasing both sibling and agency capacity around sibling needs in NYS.

Rationale and Possible Strategies: While the current study does much to shed light on the current sibling and agency needs, the funding and service context is changing so rapidly that interventions must be devised and implemented within the evolving context. Key agency and sibling stakeholders should be consulted in the drafting of the plan for feedback and validation. The strategic plan should consider available funding resources, existing policies and practices, related development needs; and human resources – especially sibling groups and other developmental disability-related groups with volunteers as resources. The final plan should list responsible parties, provide clear timelines for implementation, and include measurement of outcomes. Activities are outlined below, but will need additional consideration in order to achieve outputs and lasting outcomes.

Recommended Order of Implementation

*In general, the following implementation sequence of the capacity-building efforts outlined in this report is recommended. While building capacity, **concurrently** implement the design and dissemination of trainings to meet basic sibling training needs, making these trainings inclusive of other family members whenever possible. Consider an initial meeting of state agency representatives to investigate possible agency collaborations as outlined within in this report.*

1. Contact existing sibling database members and match them to their sibling's service agency.
2. Connect agencies to these siblings and encourage them to reach out with inclusive programming and in dialogue around sibling needs.
3. Connect the members of the current sibling database to existing sibling resources and draw on the current sibling database to locate representative siblings willing to contribute to planning and outreach strategies as remaining efforts take shape.
4. Conduct agency awareness activities, using existing sibling groups and members of the existing database (for example, panel discussions at agency conferences).
5. Develop statewide systemic data collection procedures and family-friendly processes with agencies.
6. Develop and implement training for service providers on culture and practice change around sibling involvement.
7. Develop a one-stop portal for siblings within an existing website (OPWDD or other prominent website location).
8. Develop a marketing and outreach campaign to identify siblings. Include representation from minority group leadership at the design stage of this effort.
9. Implement the marketing and outreach campaign statewide.
10. Assess progress and revise planning as needed, initiate cross- systems agency involvement now, if not earlier.

Identify Siblings

1) Recommendation: Develop a plan to increase data collection and use of information about siblings.

Convey the importance of long term planning at the initial intake, collect the names and contact information of any siblings, and discuss potential sibling involvement.

Rationale and Possible Strategies: Only 29% of the surveyed agencies indicated that they intentionally and formally record sibling information. Very few individuals with developmental disabilities have an adult sibling identified as a primary guardian, contact person, or even listed in their contact information. Only 54% of sibling respondents indicated that their primary agency had their contact information. Several focus group participants reported that they believed their sibling's agency did not have their contact information.

As both the agency and the sibling survey respondents were self-selecting, and likely more motivated than the general population, we expect the actual number of agencies formally collecting sibling information may be even less. Changing demographics and an aging population of parental caregivers indicates that agencies must pay close attention to gathering contact information for siblings.

The initial assessment system should identify an individual's current and potential family strengths and needs, including sibling supports and desired relationships. OPWDD and provider initiatives regarding service quality oversight should include information regarding family involvement, including siblings, and the connection of these family members to the achievement of personal outcomes. For this initiative to be most effective, a uniform approach to sibling data collection and retention must be adopted across agencies. This approach must include methodology to ensure periodic updating of data. It is recommended that the OPWDD system coordinate this data. If that is not currently possible, the DDPC should develop a voluntary database and engage in efforts to reach as many siblings as possible. Work with those siblings could provide evidence regarding the need for a systems- wide approach.

2) Recommendation: Develop an outreach plan to siblings, especially underrepresented siblings

There is a need to develop an outreach plan for sharing available supports and services with siblings and assisting with long term planning. The outreach plan needs to include strategies for broadly reaching siblings, especially those of lower socio-economic status and those who are members of minority groups.

Rationale and Possible Strategies: The survey respondents tend to represent a more female, white, educated and wealthy group than the population as a whole. Minority groups, especially Hispanics, are some of the fastest growing demographic groups in NYS. Although the survey was heavily promoted, results show that our attempts to reach Hispanic or other minority group siblings did not reach sufficient numbers. The population of NYS is 18% Hispanic, 42% minority (non-white or Hispanic); 71.5% are white (Hispanic or not) and 28.5 are non-white (Hispanic or not).¹ Meanwhile, 91% of our respondents were

¹ Source: U.S. Census Bureau: State and County QuickFacts. Data derived from Population Estimates, American Community Survey, Census of Population and Housing, State and County Housing Unit Estimates, County Business Patterns, Nonemployer

white, and only 4% were Black/African American and 4% Hispanic (note that respondents could select more than one race/ethnicity category).

Many of the recommendations in this report (e.g., training for siblings) will only be successful if we can access siblings and market these services to them. There is no easy way to find members of this group, but the methods used in promoting this survey can serve as a starting point. However, we were not particularly successful in reaching certain demographic groups.

Leadership of minority group communities should be identified and engaged to help provide entre to their communities. A resource document of state and community agency and community groups with bilingual capacity and connections to these communities should be compiled. Since most bilingual and minority group families are involved with the public schools at some point, the NYS State Education Department System is one agency partner that may be of help in the quest to find siblings of this demographic. There are many resources and groups connected to this state agency, such as the NYS SED Bilingual / ESL Committee of Practitioners,² the regional bilingual Education – Resource networks,³ and the NYC Preschool Bilingual / English as a Second Language Technical Assistance Center.⁴

3) Recommendation: Build upon the sibling database developed through this project.

Create ways to keep sibling contact information current, link the siblings to agencies, and grow the sibling database.

Rationale and Possible Strategies: As part of this survey, 355 siblings of individuals with disabilities identified themselves and provided contact information. As a whole, these individuals may be thought of as representing those who are more connected, responsive, and likely to be first adopters of new initiatives.

An initial goal might be to match these people with their siblings' agencies and encourage agencies to reach out to these interested siblings when developing their sibling outreach initiatives. In many areas of the state, doing this would lay the foundations for initial work. The existing sibling database can be used to market trainings, recruit future focus groups, etc.

New siblings can be added to this original data set, and the growing list kept by the DDPC or central OPWDD for future outreach regarding trainings and other initiatives. Ideally, one secure central database would house the initial database and would also include siblings identified by local agencies, added as they are identified.

Agencies could encourage the siblings that they have identified to sign up for the sibling database mailing lists to learn more about resources. We also suggest offering siblings an opportunity to join the sibling database through a one-stop sibling webpage portal, housed on the OPWDD or DDPC websites.

Statistics, Economic Census, Survey of Business Owners, Building Permits. Last Revised: Thursday, 06-Jun-2013 11:35:10 EDT. Available at: <http://quickfacts.census.gov/qfd/states/36000.html>

² <http://www.p12.nysed.gov/biling/bilinged/BilingualESLCOP.html>

³ <http://www.p12.nysed.gov/biling/bilinged/betac.html>

⁴ <http://www.p12.nysed.gov/specialed/techassist/NYCbilingualpreschoolTAC.html>

The DDPC could urge its grantees who work with families to make it a standard practice to encourage sibling involvement and to direct siblings to the sibling webpage portal.

Prepare Agencies to Provide Supports to Siblings

Develop Agency Processes and Staff Training

4) Recommendation: Provide training and technical assistance on systems development to agencies.

Assist agencies with putting processes in place to identify siblings of individuals with developmental disabilities, record their information, and reach out to them. Ensure that agencies are able to keep those records current.

Rationale and Possible Strategies: As noted earlier, very few agencies have contact information for siblings. Both sibling and agencies acknowledged on the survey the need for support for agencies to reach out more effectively to siblings. Almost 80% of agencies felt they needed support to increase sibling interest and involvement and 59% felt they needed assistance in identifying siblings; similarly, 62% of siblings perceived that agencies need support in increasing interest and involvement and 40% felt agencies need support in identifying siblings. In addition to policy change, staff may need assistance in implementing new practices in a family-friendly and effective manner.

Agency leadership must be actively engaged in developing and agency staff trained in both uniform (statewide) processes for data collection and working with families to include siblings throughout the lifespan. Ideally, this training would be provided in the same way and by the same providers to all agencies, so that fidelity of the data collection process could be ensured.

5) Recommendation: Include input from both the individual with a disability and all other family members (including siblings) when planning for family involvement.

Providers should seek to understand what matters most to the person with developmental disabilities with respect to family involvement (i.e., individual choices around desired personal life goals or outcomes). Support and service strategies/delivery should be tailored accordingly so that family members will be able to help achieve the outcomes. Planning must also respect the desired personal outcome goals of the other family members.

Rationale and Possible Strategies: The need for change in the practice culture was often alluded to within the survey and focus group responses. Focus group participants on both the agency and sibling sides felt that agency leadership and staff could benefit from listening to sibling panel presentations and discussion about working with whole family groups, including siblings. This could take place at agency conferences or through dialogue sessions for siblings to discuss issues with agencies. Siblings in the focus group brought up the need for agencies to reach out to facilitate social connections with others served by the agency, for both themselves and their sibling.

Quality improvement initiatives for service delivery agencies should focus on improving family supports and personal outcomes for individuals with disabilities. Policy makers should embed these practices in system redesign, measurement, and evaluation efforts.

6) Recommendation: Provide training to service providers on culture and practice change

Providers of self-directed planning services: service coordinators, financial management services agencies, start-up brokers, etc., need assistance to develop culture and practices that are inclusive of sibling involvement as needed/ desired by the individual and family.

Rationale and Possible Strategies: Survey and focus group information indicate a need for provider trainings related to best ways to interact with siblings as family members, as well as a lack of current training information available on developing culture and practices that are inclusive of siblings. Approximately 80% of agency respondents agreed that there was an agency need for staff training around the value of the adult sibling relationship. The majority (62%) of both sibling and agency respondents believe that agencies need help with developing sibling relevant programming.

As systems change the way services are delivered, there may be opportunities to train individuals at critical points in the change process, influencing future practice. The DDPC, OPWDD, and key training gatekeepers for self-directed planning service providers should make coordinated plans to provide these professionals with skills and tools around sibling involvement and sibling data collection.

7) Recommendation: Provide training on community building and communication.

Traditional front line residential agency and institutional staff must be educated about the important role siblings can play.

Rationale and Possible Strategies: Siblings in the focus group stated that agencies often communicate with them only when something is wrong or needs attention. Improved communication could meet the need of respondents who identified “understanding the service delivery system” (8%) and “Identifying alternatives if programs are changed or eliminated” (19%) as their greatest unmet need.

Provide guidance to these staff members on how to reach out to family members, how to build a community of providers and families, and how to communicate information about positive events with siblings. Actions that could build community include encouraging voluntary disclosure of names and providing introductions among family members of persons residing in the same facility, participating in the same workplace, attending the same events, etc. Additional efforts could include holding family day events at residential facilities and encouraging communication among family members, including introducing siblings to other siblings; and developing agency auxiliary groups (one focus group member likened these to the PTA affiliation with schools).

Agencies should also build systems to encourage periodic positive communications with siblings, providing personalized communications regarding the sibling’s progress, outside of a crisis or problem situation. This could be accomplished with a system that includes a requirement for agency caregivers to write a personal note or make a phone call to the family two to four times per year.

8) Recommendation: Develop marketing plans for reaching siblings.

Find effective ways for agencies to inform siblings about new or existing trainings or supports.

Rationale and Possible Strategies: Over half (60%) of the siblings did not know if their sibling's service provider or agency has workshops, supports or information available to them. Of those who were aware of such services or trainings, 75% found out through personal contact or mail. Only 65% of siblings felt they have the knowledge and skills needed to become their sibling's primary guardian, and this percent drops to about 55% for siblings ages 18-34, a clear need for outreach and training exists (Exhibits 4 and 5). Respondents identified many information needs, but less than half felt they knew where to find answers to their questions.

Outreach and marketing, in general, need improvement regarding sibling identification and involvement. State and local media campaigns should be designed, adopted and then disseminated. Specialized groups with outreach to minority and other hard to reach communities should be engaged in in the earliest phases of these efforts.

Many different channels of outreach should be considered. Since personal contact is so powerful, members of existing family support groups should be asked to engage in distributing materials and information to their acquaintances. Family counseling provider associations, school systems, social service systems, and other organizations should be provided basic promotional materials for distribution. Information can also be provided through public service channels. Communities have local website communication boards and local public access television stations that can be accessed free or at low cost. It is recommended that a state master listing be compiled of the contact information and distribution requirements for community public access TV stations and other public outreach avenues.

Develop Sibling Resource and Support Structures

9) Recommendation: Assist regional agencies with the development of adult sibling support groups.

Where regional sibling groups already exist, connect both agencies and siblings.

Rationale and Possible Strategies: Connecting siblings to support groups and assisting agencies to foster the development of regional support groups will build the knowledge and networking capacity of both siblings and the agencies. Fewer than half the agency's respondents were aware of youth support groups for siblings in their region, and only about a third were aware of support groups for adult siblings in their region. When aware of supports, at least 93% of agency respondents indicated that they shared that information with siblings. Lack of awareness of both agencies and siblings about sibling support is a critical barrier increasing the reach and impact of these groups.

Instead of agencies developing their own support groups, a recommended strategy is for agencies to collaborate with the local Arc and SibsNY to form support groups that are inclusive of all developmental disabilities, and perhaps including mental health disabilities or other disabilities. A larger, more disability inclusive, sibling advocacy group will have greater impact and will follow the alignment model of the

national Sibling Leadership Network (SLN). That network serves as a national leadership organization, with affiliations with The Sibling Support Project and the Arc's National Sibling Council. In NYS, SibsNY is the state chapter of the SLN and regional alignment with other disability organizations is desirable in order to build statewide capacity.

10) Recommendation: Build or adapt a set of training modules to meet sibling needs.

OPWDD representatives, another state agency, or a contracted entity should be tasked with providing customizable training modules that regional agencies could adapt for the specific needs of the siblings they serve. Consider embedding sibling components into existing modules wherever practical, and build specific trainings to meet the few siblings-only issues.

Rationale and Possible Strategies: Agencies perceive many helpful, concrete training needs for siblings exist and are important. Large gaps exist between the perceived need for a training topic and number of agencies offering the topic. For example, 92% of the agencies believe that training around aging with a disability is helpful and important for siblings, but only 28% offer such training.

Where an agency or sibling has identified that a needed training is offered, a comprehensive review of that training should be completed. Curricula and content delivery/ presentation of these existing trainings should be reviewed for applicability to and inclusiveness of siblings. Trainings should be modified where needed, shared for use in other settings across the state and adapted for online delivery.

Where needed trainings do not exist, a priority listing of needed trainings should be developed, with consideration of the Sibling Survey's stated need areas. These trainings should then be developed and disseminated widely, using marketing strategies previously identified. Trainers should be skilled in training delivery, both content and process.

Develop Sibling/Family Training and Outreach

Build Capacity of Siblings and Sibling Groups:

11) Recommendation: Connect efforts to meet sibling needs across systems.

Develop initiatives to connect sibling needs in the developmental disabilities system to sibling needs in other systems, such as schools and healthcare.

Rationale and Possible Strategies: Many sibling issues are similar across agencies. Relatively few siblings (45%) reported having any involvement in Individual Service Plan (ISP) meetings, case conferences, or other meetings regarding their sibling.

The sibling focus group felt that adolescent siblings could begin by being involved in ISP and Individualized Education Program (IEP) meetings for their sibling, or gain credits and skills related to their sibling's disability through school-based service learning.

Through collaboration with the state education system, state-sponsored parent training centers could embed information about the role of siblings in their trainings and acknowledge siblings in the circle of support for the student with a disability. This approach is both cost effective and culture changing for the next generation.⁵

Issues regarding access to medical information were discussed as well, with the need for training on how to appropriately access needed information and deal with the health care system. Other agency systems may have additional points of intersection and this should be explored with representatives of those systems.

12) Recommendation: Increase capacity of existing sibling assistance organizations through intentionally fostering statewide cross-collaboration among sibling groups.

Improve the ability of these organizations to support siblings across the state. Foster development of traditional organizations and social media based groups and encourage traditional sibling involvement groups to develop the use of social media outreach tools and strategies.

Rationale and Possible Strategies: Although the population that responded seems to represent the demographic most likely to participate in sibling networks, fewer than 15% of the respondents reported having heard of any named sibling support groups or networks. When asked if they would be interested in support groups for siblings, although many respondents responded “maybe,” many were interested in support groups open to siblings. There was a fairly even breakdown in terms of preference for online, regional in-person and blended structures for groups.

Organizations such as SibsNY have demonstrated interest and have a personal stake in the issue, but cannot currently reach or impact a statewide audience effectively. They may need assistance to develop outreach strategies, capacity, and sustainable growth plans. Most sibling organizations are headed by part-time volunteers who would have difficulty forming and sustaining larger support groups, especially groups utilizing various modes of social media and providing substantial programming.

The DDPC may be in the best position to lead initial meetings or collaboration planning of regional groups. Existing statewide networks and organizations such as NYS Partners in Policymaking, the ARC, and the NYS Self-Advocacy Association should be encouraged to help sibling groups such as Sibs NY expand by coordinating their existing efforts.

As noted, the resources of existing sibling groups are limited. However, though leveraging collaborations with other sibling-focused and developmental disability-focused initiatives, the reach and impact of these groups can increase. The ARC has an existing partnership with the Sibling Leadership Network (SLN), including the SLN state chapter, SibsNY.

Partners in Policymaking® is actively building a sibling caucus group consisting of leaders engaged in sibling-specific organizations. The Partners effort to help siblings through coalition building is intended

⁵ Information regarding the NYS Special Education Parent Centers may be found at <http://www.p12.nysed.gov/specialed/techassist/parentcenters.htm>

to act as an incubator of sibling leaders, providing them with additional statewide base. This initiative is in the second year and is beginning to form a small nucleus of interested participants. There are three sibling leaders in this year's class and the Partners program now includes the NYS delegate to the Sibling Leadership Network and the lead of SibsNY, as well as persons connected to SibShops.

Deliver Sibling trainings – Address Delivery Process Needs

13) Recommendation: Develop a user-friendly web portal on the OPWDD site, or other prominent website, offering access to all sibling resources.

Siblings need a one-stop service portal for their needs, and none currently exists that is connected to the delivery system.

Rationale and Possible Strategies: The developmental disabilities service system is confusing, and many siblings have no understanding of how it works; this was clear from focus group meetings and the number of respondents who noted that their greatest needs were around better understanding the service delivery system. A sibling page on an OPWDD or other prominent website can meet that need and would be able to house asynchronous trainings (web based instruction of many types, accessible at any time) offering basic overviews of how siblings can be involved.

To attract and inform people new to the system, it will need to be both well-advertised and feature a clear and simple design. In addition, it could allow siblings to identify themselves and sign up to receive information in the future, thus serving as a way to build the existing sibling database while ensuring siblings feel a connection to the system. The people who most need to know where to obtain information and training are digital natives, comfortable with technology as a result of being raised in an age of ubiquitous technology use (aged 18-34), making a web-based tool such as this an appropriate approach.

The website could provide, for example: 1) an overview of the current service delivery system, 2) a FAQ with a list of current resources and descriptions of changing systems for adult siblings, system access and delivery structure basics, 3) basic information regarding self-directed, agency- managed, and combination service option,. 4) annotated links to available generic trainings (e.g., guardianship), 5) sibling support resources and organizations in NYS, 6) an interactive map of resources and contacts, and 7) an option for siblings to sign up for the siblings database to receive additional resources and announcements.

14) Recommendation: Make family trainings intentionally inclusive of siblings and other family members.

Trainings for family should include members beyond parents, embedding concrete materials and language that recognizes siblings as part of the care decision-making circle.

Rationale and Possible Strategies: Sibling participants in the focus groups felt sheltered from decision-making by parents/family, and were therefore not prepared to take on this responsibility. The practice of including siblings as a natural part of the family circle of support will raise the acceptance of siblings in that circle and will change the language, attitudes and other cultural components of the system of care. It is also more cost effective to include siblings in family trainings whenever practical, instead of providing additional stand-alone training. The sibling focus groups indicated this as a need area.

New or redesigned content area trainings should embed process information on the role of all family members in choice-making and person-centered planning. Developmental disabilities system agencies dealing with parents and the NYS State Education Department Parent Centers should provide information for parents about how to involve adolescent siblings in planning discussions and preparing for future guardianship planning – a life-course approach.

15) Recommendation: Create trainings and supports that will accommodate a variety of sibling life variables and need situations

The system needs to develop flexible trainings that will meet people where they are in the planning and caregiving process.

Rationale and Possible Strategies: Both siblings have complex lives and may not be able to plan or access trainings in a manner that professionals would advise. Siblings need a variety of service and training delivery systems that break through the barriers to their involvement, such as time constraints, transportation, and cost of travel. These trainings should be offered through multiple pathways, including online options.

Nearly two-thirds of respondents indicated an interest in “online training – at my own pace, own time”, while less than one-third were interested in “face-to-face training at regional locations”. Focus group discussions highlighted the varying needs of siblings, some siblings want to remain anonymous, others want support groups, some find that they need support groups only as part of a developmental passage; others want them throughout the life course. Sometimes siblings understand the need to be proactive, and want to access planning trainings well in advance of immediate need. On other occasions, they may find themselves seeking instant information in order to avert trouble or cope with an urgent situation. Therefore, both topics and supports should exist in a fluid environment, accessible as needed to those in need.

A variety of online training delivery systems should be developed, including webinars, archived materials and handouts, online coursework, online discussion boards, blogs, social media use, etc. It is important that a systematic media implementation plan be developed prior to developing the trainings and that all relevant information be linked together in a user- friendly web environment.

Deliver Sibling Trainings in Needed Topic Areas

16) Recommendation: Provide training and concrete information on basic topics and processes.

Siblings need preparation for a variety of circumstances (guardianship, wills, trusts, benefits, aging, social supports, etc.). Provide siblings with assistance to determine which options and trainings are right for them and differentiate the instruction for siblings as needed.

Rationale and Possible Strategies: Sibling respondents are generally willing to become the primary contact person for their sibling, but only about half of the siblings age 18-34 feel ready to become their sibling's primary guardian. A clear need for outreach and training exists around basic topical issues to prepare siblings for these critical roles.

Some topic area needs are more important to specific groups of siblings, depending on age, region and other demographic categories. However, needs are more related to both siblings' life situations and stages than specific ages. There are also significant crossovers in the needs of various sibling groups and the content of parent trainings. Much family training can be made inclusive of siblings, as outlined elsewhere in these recommendations. While some trainings may be utilized more heavily by some regions or specific age groups, all core trainings should be offered statewide, and in both online and face-to-face presentation modes whenever possible. Foreign language translations, especially Spanish, should be considered for key publications and trainings. All trainings should be culturally sensitive and sensitive to the economic resources of individuals.

For siblings with an older or more fragile sibling, provide information on aging with a disability and end of life planning, health care proxies, wills and living wills, survivor planning, etc. One of the greatest areas of need for siblings who are aging is information regarding how to navigate this life stage. At this stage, some focus group participants indicated that they have less need for general support groups, but more needs around developing stable and satisfying relationships for themselves and their sibling. Although the survey found that regional needs are not generally very different, aging with a disability is the topic that showed the more regional variation, with 84% of respondents in NYC indicating a need for information, resources or training on aging with a disability compared to 56% in Long Island.

17) Recommendation: Provide immediate training on the Home and Community Based System and on alternatives to sheltered workshops.

Although not a topic of immediate concern when the survey was designed, this was mentioned in the focus groups as a critical, immediate need for a segment of siblings whose brother or sister will be affected under the current restructuring plan. Other family members may also have this need, so siblings may be able to be included in a broad audience training.

Rationale and Possible Strategies: There is an immediate need to help siblings of persons living in institutional care understand current and future housing options under the Home and Community Based System. Siblings of persons working in sheltered workshops or planning to work in sheltered workshops also have a vital need for information on how to access alternatives.

This is of greatest concern to those adult siblings who fear life disruption for themselves and their sibling and want to be proactive in their planning. As the system shifts, it is important to provide trainings to this group to both relieve stress and prevent potentially uninformed decisions.

18) Recommendation: Provide specific transitioning training.

For those who are not yet guardians or who have parents who have always sheltered them from the decision-making role, provide training on how to talk with their parents about the future, about their changing role with their sibling and about planning the move into a supportive decision-making role. For parents, provide outreach and training on transitioning to adult sibling involvement, and sharing their role.

Rationale and Possible Strategies: The focus group participants indicated that parents can be barriers to sibling involvement. Parents may have a strong bond with the sibling with a disability and not welcome involvement, or they may be protecting both siblings from concerns and responsibility. Some siblings expressed desire for training and support to address these issues with their parents in a timely manner. For trainings which are sibling – specific, involve core stakeholder groups of siblings with similar experiences and train them to lead or assist with strategy development. Consider utilizing a mix of the current sibling leadership and other individuals of diverse backgrounds and provide follow- up support network links and facilitation.

19) Recommendation: Provide trainings on communication with the provider system.

Siblings need to have enough knowledge to navigate the system, skills to get the information and services they need, and know where and to whom to appeal if unhappy with an outcome.

Rationale and Possible Strategies: Siblings identified communication concerns throughout the focus group sessions. These concerns related to both acquiring information and getting questions answered about the information they have received. There was an undercurrent of concern that they did not feel they knew enough to evaluate the presented options for their sibling, and they did not have enough independent information to know if other options could exist.

Trainings should instruct siblings on how to access and communicate with service coordinators, financial management services agencies, start-up brokers, etc.; how to talk to agencies regarding what agencies can offer siblings; how to talk with agencies about concerns; and where to go if dissatisfied with an agency or service.

20) Recommendation: Provide training on life balance with your sibling & dealing with changes.

Siblings need strategies to keep their own finances, family, personal and work needs functioning while helping their sibling and planning for the future.

Rationale and Possible Strategies: Siblings expressed concern regarding their time and personal life demands in relationship to their sibling: 26% indicated that their greatest unmet need was the general future planning process, followed closely by 22% indicating that balancing their sibling relationship with work/life demands was an issue. Financial concerns and planning for social supports and opportunities

were high on the overall list of needed trainings and information and were discussed during the focus groups. These training topics could also be delivered or supported through sibling peer networks. Training should also address strategies for appropriate action when service options change or crises occur and adjusting to maintain balance in both siblings' lives.

The preceding recommendations and implementation strategies are based on what the needs assessments revealed as the areas of greatest need in the sibling and agency community. We firmly believe that developing a plan for implementing these recommendations, with input from stakeholders and incorporating the evolving context of the developmental disability system, will lead to better outcomes. Considered as a whole, these recommendations are the first steps toward improving the lives of siblings (both with and without developmental disabilities) and the service delivery system process and culture.