The second in an ongoing series of articles on supporting individuals and the families they live with...

Uncharted Waters:
Moving Beyond What We Know as Family Support

By Michelle " Sheli" Reynolds, Ph.D.

Easter last year, my siblings and their families had gathered to celebrate the holiday, while my parents were on a much-deserved vacation. To many of you this many not seem extraordinary; however for parents that have a child with a disability this event is monumental. For my parents, this was much more than their adult children celebrating a holiday together; it represented a glimpse into Eric's future and that he will always be an integral part of our family, even when they are not there to orchestrate his inclusion.

Although this is my story for this stage of our family journey, this story is just one example of the many different ways to define family support. Every family that has a child with a disability has their own story built upon their own complexity and diversity. As a field, it is critical that we recognize the importance of the different stories that have meaning in families' lives, and by doing this we can identify how we can play a role in supporting each family on their own journey. This approach will require recognition that family support evolves with each stage or transition of the family's life together and is further defined within the context of that families own culture, membership, value-base, and environment.

Now, what does this really mean? How, as a field, do we apply this concept? Family support has been something we have discussed and believed we were implementing for many years; however, from the perspective of families we still have not fully succeeded in implementing the supports they need. As the service system evolves and frees itself from its historical design of providing institutional care to a system that supports self-determination, freedom, and choice for people with disabilities, it is imperative that we recognize and support the significant role families play throughout the lifespan. We must remember that families are and have always been the constant; it is not families that have changed but the service system and society's response to disability.

Recently, a group of national stakeholders came together to develop a definition for supporting families that will serve as the foundation for this new generation of family supports that builds on what we have learned from families. The purpose of this group is to develop a national movement that includes policy to create an infrastructure that supports the family across the lifespan. The goal, as defined by the National Agenda on Family Support (July 2011), is:

> To support families, with all their complexity and diversity,
> in ways that maximize their capacity, strengths and unique abilities
> so they can best support, nurture, and facilitate
> the achievement of self-determination, interdependence, productivity, integration, and inclusion in all
> facets of community life for their family members.

To begin defining family support, it important that we remove any blame or judgments from the conversation. We must be proactive and focus the conversation on where we want to go while also recognizing the lessons learned from our past so we do not make the same mistakes again. To frame this conversation, I have used the categories of "charted, slightly charted, and uncharted." This

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framework offers the option of incorporating any of these past or new options that have been available to support families; however, it does not suggest a continuum or menu--rather it is an attempt to lay out options that may or may not be considered if relevant.

The purpose of the "Charting Family Support" framework is to facilitate a conversation between stakeholders that recognizes that we are moving into "new water," which will require everyone to work together and build upon strengths. When traveling into uncharted waters, everyone on this journey is using a new map or often no map at all. Everyone must recognize that we will make mistakes and we will need to try different strategies before we end up at the final destination. The following table highlights the new map of family support focusing on areas that may differ from our current understanding of family support.

Map of Family Support		
Specifics	**Past, Charted**	**New, Uncharted**
Who Defines	Defined by service system as a billable service or eligibility criteria	Defined by self-advocates, families, the disability service system, and other stakeholders
Who Benefits	Focus on caregiver or parent	Focus on family unit. Family defined functionally, inclusive of siblings, parents, parents with disabilities, grandparents, friends, extended family members
Self-Determination	Tension between self-advocacy and family support	Family support enhances opportunities for self-advocacy and self-determination
Focus of Support	Crisis, immediate response	Preventative, long-term futures planning
Goal	Supporting caregiver in order to decrease demand on long-term services	Quality of life for person with ID/DD and their family in the community with supports needed for the best possible life

The design of this new infrastructure of family support is not a program or service of the disability service system; it is an infrastructure built upon the resources in the community that is responsive to the family. It requires elements from all aspects of the community that can be accessed across the lifespan. The disability service system is an important component but its role and responsibility must adjust to supporting families and community members in planning and developing for possibilities and dreams before crisis and life-transitions. This infrastructure builds upon collaboration and relationships at the individual, organization, and community levels.

The essence of this infrastructure is the overall philosophical way of providing support to families. The family system, including its strengths, capacity and diversity, determines the types of supports and services that are needed. Together the individual with a disability and their family identify and utilize their

existing relationships and resources, as well as developing strategies for establishing new connections. This value-based approach to supporting families is the foundation for many of our current organizations; however, it is important to be clear how this philosophy resonates in practice.

More specifically, a family support infrastructure at a minimum should integrate the following types of support: instrumental, emotional and information/training. These supports, when coordinated and comprehensive, can enhance a family's capacity to provide day-to-day care, decrease their feelings of isolation, and increase the possibilities for the future. These supports come in many different forms, provided in combination or individually by many different stakeholders, and should occur throughout the lifespan.

Elements of Family Support Infrastructure
An overall value-based approach to providing services to families and their family member with ID/DD: ▪ recognizes the family as a system ▪ driven by the family and family member with ID/DD ▪ focuses on the strengths, capacity and diversity of family ▪ builds on the networks of all family members and community

Instrumental Supports: *Day-to-Day Needs*	**Emotional Supports**: *Mental Health and Self-Efficacy*	**Information and Training Supports**: *Knowledge and Skills*
- Respite/Childcare - Adaptive Equipment - Home Modifications - Financial Assistance - Service Coordination - Cash Subsidies - Person/Family-Centered Planning	- Parent-to-Parent - Self-Advocacy Groups - Sib-Shops/Support - Support Groups - Professional Counseling - Nondisability Community Support	- Information on Disability - Knowledge about Best Practices and Values - Skills to Navigate and Access Services - Ability to Advocate for Services and Policy Change

Instrumental supports are the services that most people think of when thinking about family support; the day-to-day concrete services needed to support a child in the family home, such as respite, home modifications, cash subsidies, etc. These supports assist the family with the physical aspects of caring for their family member at home. These supports are necessary and very real; however, as a field, we have a tendency to only focus on these supports and overlook the emotional and informational needs that could be just as great for many families.

How often have you heard a family say, "I feel so alone." or "I don't know how to navigate the maze of services?" Most families express the need to know more information and to connect with other families

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but they are unsure of how to get this need met. We can address the emotional and informational needs of families by connecting them to other families, training opportunities, support groups or to professional services, if needed. In most states, family organizations such as parent-to-parent, family-specific, or diagnosis-specific organizations, are available to work with state service systems to meet these needs. An infrastructure for family support would include these types of organizations as key stakeholders working with the state service system to identify strategies for accessing and funding these services in the most seamless and integrated manner, whether they occur within or outside of the disability service system.

A Map of Supports and Services			
	Charted	**Slightly Charted**	**Uncharted**
Housing	▪ Institutions ▪ ICF ▪ Group Homes	▪ Independent Supported Living ▪ Home of Your Own	▪ Shared Living ▪ Co-Op ▪ Planned Living Space in Home
Meaningful Day	▪ Sheltered Workshops ▪ Day Habilitation	▪ Supported Employment ▪ Volunteerism	▪ Micro-enterprises ▪ Career development
Direct Care and Support	▪ Hired Direct Care Staff ▪ Personal-Care Attendant	▪ Family/Self-Directed Services ▪ Respite ▪ Natural supports ▪ Micro-boards	▪ Tele-Care ▪ Exchange Networks ▪ Time Banks ▪ Human service cooperatives
Planning and Coordination	▪ Coordination of State Services by a Case-Manager Based on Current Needs	▪ Facilitated Outside of System ▪ MAPS, Futures Planning, Person-Centered Planning ▪ Special Needs Trusts	▪ Long-Term Planning Inside/Outside of System ▪ Financial Security and Planning ▪ Life Coach ▪ Plans Facilitated by Family Leaders ▪ Support Brokers
Safety	▪ Guardianship	▪ Alternatives to Guardianship ▪ Self-Advocacy Skills	▪ Self-Determination ▪ Social Capital

A family support infrastructure would also assist families in becoming more knowledgeable about options and the application of best practices across the lifespan. This information would move beyond outlining a

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menu of services. It would assist families in understanding and making new options a reality. This infrastructure also requires that we move beyond defining best practices, such as person-centered services, social-capital, self-determination, integration, and inclusion, to truly helping families understand and apply these concepts. An infrastructure of family support provides information and training on these key concepts but it also has strategies and mechanisms for assisting families in making these practices a reality. Families must have an opportunity to see, feel, and trust these practices before they can apply them to their own family.
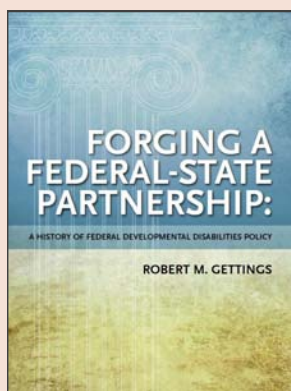
An "uncharted" life, less dependent on long-term publicly funded disability services, requires a new understanding for families at a very early point. It is important to discuss with families a map of realistic options with facts about funding realities and services required for accessing them. The following map provides examples of options that may be available to individuals with developmental disabilities and their families across different areas of life. For each of these elements, you should ask yourself: is this option in my state, do professionals and families know what it is, is there a mechanism for implementing this option, is there funding or a policy that supports this option, what changes needed to happen to make this a reality for families?

A family support infrastructure requires the commitment of all stakeholders working for the common goal of supporting families so they can support their family member with a disability. Although developing this infrastructure may decrease some of the demands currently placed on service systems, the reason for the focused interest in family support is that families have been requesting this support for a long time. Families want to support their child with a disability throughout the lifespan to have the best life possible; however, what is currently available to support families does not align with the strategies needed to make this dream reality. Regardless of what has brought us to this point, it is time to develop a new infrastructure for supporting families and ultimately enhancing the quality of life for individuals with disabilities. Now is an exciting time for all of us to work together to transform and develop this new way of supporting families. I know for my family, this type of infrastructure would support us in giving my brother the life he deserves.

If you are interested in learning more about or joining the National Agenda on Family Support, please sign up for updates at www.familysupportagenda.org. ✎

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Future issues of CSR will feature additional articles about supporting individuals and the families they live with.

Forging a Federal State Partnership, NASDDDS and AAIDD release new publication. This ground-breaking study of the revolutionary changes in public policy toward persons with intellectual and developmental disabilities over the past fifty years is written by Bob Gettings, former Executive Director of NASDDDS, an active participant in the events. ($35/NASDDDS Members; $50/NonMembers)

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