



# FAMILY SUPPORT: COMING OF AGE

## FINAL REPORT AND RECOMMENDATIONS

*Identifying the support needs of people with Intellectual/Developmental Disabilities or Traumatic Brain Injuries and their aging caregivers in North Carolina and the barriers involved in attaining that support.*

**North Carolina Council**  
on Developmental Disabilities



*A First In Families of North Carolina Initiative  
Funded by the North Carolina Council on  
Developmental Disabilities.*

# INTRODUCTION

Dear Stakeholder;

North Carolina is facing a perfect storm with the confluence of persons with Intellectual/Developmental Disabilities (I/DD) or Traumatic Brain Injury (TBI) living at home and the aging of their primary caregivers who themselves are in need of more support. Over 71% of all adults with I/DD in North Carolina live in their family home. Of this percentage, 25% of their caregivers are over the age of 60.

This is a nationwide epidemic not unique to North Carolina. By 2030 the number of Americans over 65 is projected to grow by 30 million (a 67% increase in (Thaler, 2011), substantially increasing the need for paid caregiving services for those who are aging and/or have disabilities in the US.

As aging caregivers increasingly need caretakers of their own, they also need support so their loved one can remain at home and in the community, and access to Future Planning resources.

The issues of family support and Future Planning require intense collaboration between Aging and DD stakeholders. No longer can the two systems operate as silos. As individuals with I/DD and/or TBI age they too require extensive and unique solutions for accessing their communities.

The NC Council on Developmental Disabilities recognized that North Carolina currently does not have the capacity to meet the projected needs of its citizens who are aging and have I/DD, or their caregivers. Because of this, the Council provided funding to First In Families of NC to explore the issue and provide recommendations for meeting the needs of this population.

As part of that grant, FIFNC convened a Taskforce of dedicated professionals from I/DD and Aging service sectors, policy-informers, caregivers, and self-advocates. This group worked diligently to identify the needs of those with I/DD and their caregivers as they age. Staff from FIFNC and volunteers conducted a statewide poll to identify common concerns and shortcomings within our system. They met one-on-one with families from Shelby to Henderson to discuss their current and future needs as well as the availability and accessibility of resources needed to meet those needs.

This report serves to shed light on the family support needs of aging caregivers in our state, to honor the resiliency of North Carolina citizens, to humanize the caregiver crisis, and to advise the North Carolina Council on Developmental Disabilities and its constituents on the next steps toward providing the critical supports necessary to minimize “storm damage” to individuals with I/DD and their families and prevent a profound economic crisis.

Thank you for your foresight in beginning this conversation, for entrusting FIFNC to manage this initiative, and for your commitment to the over 109,000 (Braddock, 2013) individuals with developmental disabilities and their families throughout North Carolina.

Sincerely,



Betsy MacMichael  
Executive Director  
First In Families of North Carolina

# INITIATIVE SUMMARY

First In Families of North Carolina was awarded a grant from the NC Council on Developmental Disabilities to address the issues of individuals with intellectual and developmental disabilities (I/DD) and/or Traumatic Brain Injury (TBI) as they age with their caregivers. The active grant period was July 1, 2012 – June 30, 2014.

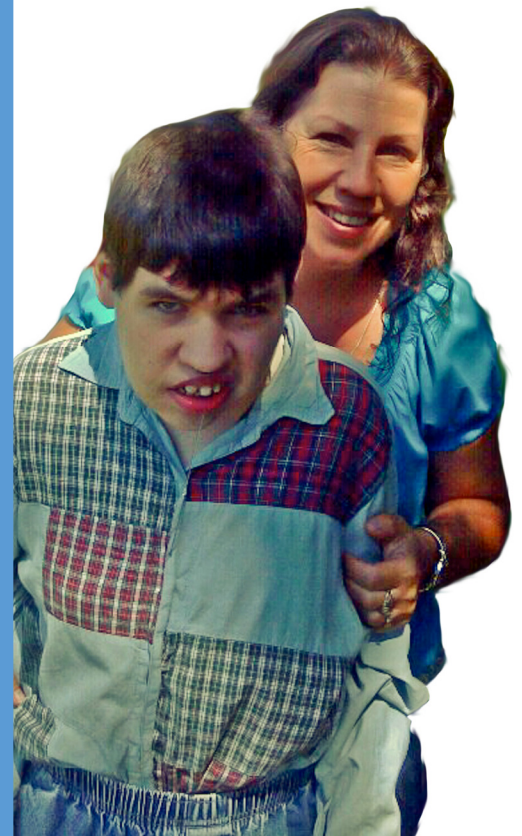
The proposed outcomes of the initiative were:

- Aging individuals with I/DD and their caregivers will have greater knowledge about, and access to, natural supports.
- Legislators and other policymakers will be better equipped to create policies that will reduce barriers (identified by the stakeholders) to obtaining family support whether through natural or more traditional services.
- Through increased collaboration, I/DD and aging system professionals will have a greater array of resources that they can refer to those they serve, thus reaching more people.
- Families will be more knowledgeable about how to plan for the future.
- Families and individuals with I/DD will have more opportunities to give back to others as valued community members.

## FAMILY SUPPORT DEFINITION

2011 WINGSPREAD REPORT

*The overall goal of supporting families, with all of their complexity and diversity, is to maximize their capacity, strengths, and unique abilities so they can best support, nurture, love and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members.*



# INITIATIVE IMPACT AND FINDINGS

To advise the grant work FIFNC formed a Taskforce comprised of professionals from the Aging and Intellectual/Developmental Disability (I/DD) service sectors, caregivers, and self-advocates. The Taskforce's first meeting was held in October 2012. The grant initiative and scope of work were presented, along with a history of previous national and state-lead projects to bridge Aging and I/DD sectors. Throughout the grant the Taskforce provided direction, reviewed and synthesized data received through survey and Future Chat conversations, advised staff on next steps in the work plan, and formulated policy recommendations. Three subcommittees of the Taskforce were formed to focus on three distinct perspectives of: policy, community/natural supports, and individual/family.

## Identifying common caregiver needs

The initiative identified common needs of people with disabilities and their caregivers as they age through an online survey distributed in collaboration with Aging and Disability partner organizations statewide. The survey, distributed statewide and conducted in December of 2012, received 277 unique responses from individuals living in 55 of North Carolina's 100 counties. Respondents were asked to choose the category they most identified with. 30% responded as professionals in aging, 12% as professionals in I/DD, 17% as primary caregivers to a person with I/DD who is not over the age of 60, 9% as family members (not primary caregiver) to a person with I/DD, 7% as family members of person who is aging, 4% as caregivers to a person with I/DD over the age of 60, and 2% identified as self-advocates. 19% of respondents identified primarily as community members. (FIFNC, 2012)



## TEEDY

*"I don't want to live in a group home all my life. Will my brother and sister support me in my desire to not live in a group home?"*

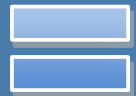
*(Durham County)*

## SURVEY FINDINGS

45%

Felt they did not currently have the supports necessary to live how and where they want

Access to Natural Supports equally as important as Formal Supports



#1

Choices on Where to Live Most Important

# INITIATIVE IMPACT AND FINDINGS

## Families need a variety of formal & natural supports

Key findings from the survey include:

- Survey participants rated access to formal (government) supports and access to natural support as equally important.
- When asked “What are the most important needs for individuals with I/DD who are aging and their aging caregivers?” respondents ranked “choices on where to live”, “financial security”, and “respite and caregiver support” as the top three among twelve.
- 41% of respondents stated that they felt that they **currently had** the supports necessary to live how and where they want, 45% stated that they **did not currently have** the supports necessary to live how and where they want and 14% were **unsure** if they had the supports necessary to live how and where they want.

## Personal support networks are vital to Future Planning

Twenty-five Future Chat conversations were conducted in-person by staff and volunteers throughout the state. These conversations facilitated a more personal and in-depth exploration of the challenges faced by real families and better served to illustrate the needs identified through research and survey. The conversations also allowed the interviewer to assess the future-planning readiness of each family and, when appropriate, provide information on future-planning resources available to them.

In Future Chats caregivers reported that they worried about not only the availability of care for their child, but also expressed concerns about having people in their child’s life that know him/her and can provide companionship and guidance once they are no longer around. Self-advocates echoed this desire for a network of support and meaningful relationships.

### RATIONALE FOR FAMILY SUPPORT

**109K** NC Adults with I/DD who live at home

Receive Public Support from I/DD Agencies

**8%**

**25%** NC Caregivers over age 60

### KAREN

*“I want to find true love.”*  
(Durham County)



# INITIATIVE IMPACT AND FINDINGS

Natural and community (non-paid) supports can provide more organic and positive outcomes for the individual with I/DD. One family shared their son's experience living with Down Syndrome in the Siler City community. Melba D., 76 has helped her son, Todd (age 36) to develop a personal network of friends and "surrogate" family that she is confident will continue to support him throughout his life. Todd has worked at Bestfood Cafeteria in Siler City since his teenage years and has made many friends through his work. In addition to having completed legal and financial Future Planning to ensure her son's needs are met, Melba takes great solace in the peace of mind that Todd will continue to be supported after her death to remain in the community he loves.

The Council on Quality and Leadership, Personal Outcome Measures concludes "Natural support networks are groups of people whose commitment to support each other is usually lifelong. These support networks cannot be manufactured or created. They can only be nurtured as they grow and evolve over time. Families provide lifelong support and a safety net for many people. Lifelong relationships with non-family members are also part of the support" (The Council on Quality and Leadership, 2000).

## THE COST OF CAREGIVING

UNIVERSITY OF ILLINOIS AT CHICAGO

DEPARTMENT OF DISABILITY AND HUMAN DEVELOPMENT

Over 71% of adults with I/DD live with family members and about 25% of these family caregivers are over age 60 years. In North Carolina, over 109,000 people with I/DD live with family caregivers – and over 25,000 of these caregivers are age 60 or over. Yet, only 13% of families providing support to members with I/DD nationally and only 8% in North Carolina (9,175 families) received public support from state I/DD agencies. Unpaid family support is a large slice of the US economy, estimated at \$450 billion in 2009. More than 40 million family caregivers provide over 40 billion hours of unpaid care to family members who need assistance with activities of daily living. Most of these families provide 50-80 hours of help each week (Heller, 2014)

## Supporting Individuals means Supporting Families

With the implementation of Managed Care for Long Term Support Services in North Carolina, the Council asked FIFNC to extend the scope of the grant work to include research on outcomes, opportunities and emerging best practices nationwide. Through collaboration with the Department of Disability and Human Development at the University of Illinois, a policy brief on Long Term Support Services in Medicaid Managed Care was created.

This brief provided national and state data to support the necessity and relevance of comprehensive whole-family support in a Managed Care environment.



# INITIATIVE HIGHLIGHTS

The Family Support: Coming of Age Stakeholder Taskforce met four times in person over the course of the grant work. Partners from the aging service sector were especially involved in the work and eager to provide opportunities for cross-training.

Through these collaborations with regional Area Agencies on Aging (AAA), Community Resource Connections (CRCs) and the Division of Aging and Adult Services at the Department of Health and Human Services, FIFNC project staff participated in comprehensive Options Counseling training and provided cross-training on the I/DD and TBI populations in various settings, including the 2013 North Carolina Association on Aging Conference, the 2013 AAA Director's Annual meeting, and the Chatham-Orange and Wake CRC Chapter meetings.

Partnerships with colleagues in aging services also provided the opportunity for FIFNC staff to play an integral role in the formation of an entirely new CRC for Durham County residents who are aging or living with disabilities. FIFNC remains involved in the Triangle-based CRC initiatives and was the lead organization representing disability services in advocating to the Durham County Commissioners for county funding for a coordinator position for the new Durham CRC.

Conversations with self-advocates and caregivers who self-identified as aging, and data collected through the online survey allowed staff to:

- obtain a comprehensive view of the needs of aging caregivers throughout North Carolina,
- to identify areas in which natural supports were being utilized successfully,
- further inform the work of the Taskforce.

## Future Chats & Checklists

In many areas of the state, especially rural communities, natural support networks compliment and reduce reliance on public supports.

Families were eager to share their personal experiences, their hopes and their fears about what the future may hold for their loved one with I/DD or TBI. Families expressed satisfaction with the Future Planning Checklist created as part of this initiative, many sharing that it helped them move forward with putting a plan in place by presenting the information in a concise and approachable format.



## INITIATIVE CHALLENGES

Council staff requested an addition to the scope of work to include national policy perspective in the wake of North Carolina's newly implemented Managed Care System for MH/DD/SAS. In addition, the loss of the staffing position for the Timebank required FIFNC to reconsider its original plan to use the Timebank as a platform for natural supports for aging caregivers. While FIFNC still believes the Timebank is an innovative way to help meet the basic needs of families (cooked meals, home repairs, ride-sharing to doctor's appointments) and embodies the FIF tenant of reciprocity – for the purpose of this initiative it was not pursued.

Three Future Planning Workshops were scheduled throughout the state that focused on providing information to aging caregivers on Wills and Estates Planning. The first was held in Shelby in November of 2013, the second was held in Winston-Salem in April 2014 and the final was planned for New Bern in June 2014. Unfortunately, the New Bern workshop had to be cancelled due to low registration numbers. While grant staff and Taskforce members worked to promote the workshop through all known channels, low registration could be in part due to the location of the workshop and/or not having made enough relevant connections in the area. It also occurred to staff that perhaps an initial workshop on Wills and Estates Planning might be overwhelming for those individuals who have not previously been exposed to discussions on Future Planning. Especially in rural areas, it might be better to focus on a general "Future Planning" information session in a small group meeting so as not to overwhelm participants.

## RECOMMENDATIONS

### **Recommendation One:**

#### **Identify Barriers to Future Planning for Caregivers of Individuals with I/DD**

To continue and build upon the research provided through the Family Support: Coming of Age initiative the Taskforce advises the North Carolina Council on Developmental Disabilities to consider funding future initiatives that identify specific barriers which lead to reluctance in Future Planning for caregivers of individuals with I/DD. Once barriers to Future Planning are identified the Taskforce recommends implementation of a pilot incentive program for families who are actively completing Future Planning Tasks.



### **Recommendation Two:**

#### **Require Future Planning as a Component of Every Person Centered Plan**

To ensure that families are knowledgeable about the necessity of planning, to decrease the need for emergency public-funded services and to provide an easier and more self-directed transition for individuals with I/DD or TBI upon the loss of their caregiver the Taskforce recommends that the Department of Health and Human Services, Division of Mental Health, Developmental Disabilities and Substance Abuse Services require that Future Planning be included as part of



every Person Centered Plan for individuals with I/DD and TBI. LME/MCO Care Coordinators, Community Guides and service provider staff responsible for Person Centered Planning should receive adequate training to have discussions about Future Planning with the families they serve. It is recommended that the design of questionnaires correlate to the age of the person with the disability. For younger families the requirement to plan could simply mean that they have been offered resources to start thinking about what they will be needing to do in the future, and what people need to know now, in the event of their premature death. As they age, the requirements should be much more specific.

## **Recommendation Three:**

### **Provide access to information and resources on Future Planning as a Medicaid Billable Service through the LME/MCO network.**

To provide access to all caregivers on resources specific to Letter of Intent, Wills and Estates Planning, Special Needs Trusts, and personal asset mapping of their community through publications (Future Planning Checklist, FIFNC, 2013), provider education and regionally sponsored workshops, the Taskforce recommends that Future Planning be considered a billable service through Medicaid and implemented in all geographic areas of North Carolina through the established LME/MCO channels.

## **Recommendation Four:**

### **Identify older family caregivers to provide resources before the point of crisis.**

It is speculated that there are many “unaccounted for” caregivers who are aging and have heretofore remained invisible because they are unaware of, or reticent to enter the formal system to access services and support. At the point of crisis is when their presence becomes known. Utilizing community mapping proactively will allow LME/MCOs, providers of direct family support such as First In Families of North Carolina (FIFNC) and existing collaboratives such as the Community Resource Connection (CRC) initiatives to identify caregivers who are aging. Educating these caregivers (once found) about available community resources could decrease reliance on more costly emergency supports, provide an opportunity to engage caregivers about the importance of Future Planning and help families to remain together longer.

## **Recommendation Five:**

### **Continue and increase cross-training and collaboration between Aging and Disability sectors.**

As formal service resources will never be adequate to meet the needs of all families, in



## RECOMMENDATIONS

part due to the “perfect storm” and because the needs of individuals and families exceed the limitations of the public sector, it is imperative that partners in the Aging and Disability fields do a much better job of understanding and supporting one another. Coming of Age Taskforce Members have committed to continuing in an advisory capacity to assist in future endeavors supporting cross-training between Aging and Disabilities. It is recommended that additional partners be recruited for this effort in order to maximize outcomes for individuals with I/DD and their caregivers.

## CONCLUSION

The Family Support: Coming of Age initiative has been successful in identifying the needs of aging caregivers and individuals of I/DD in North Carolina. Now it is time to prepare for the storm. The recommendations and findings included in this report are intended to provide the North Carolina Council on Developmental Disabilities with a foundation for next steps in preparing for the future of individuals with I/DD or TBI and their caregivers. With an anticipated growth of 67% over the next 15 years in the population over 60, FIFNC and its partners urge the Council to use these recommendations as a starting point for future initiatives and to advise policy.



---

### ARNOLD

---

*Arnold had a promising career as an electrician when he suffered a Traumatic Brain Injury in a motor vehicle crash in 1997. Three years of hospitalization later and requiring around the clock care, Arnold’s parents brought him to his childhood home in Shelby.*

*Arnold’s father Jerry is a tireless advocate for his son. At age 68, he and his wife worry constantly about who will care for Arnold when they are no longer able. Like all aging parents they want to know that Arnold will continue to be cared for, supported and engaged in his community.*

*Arnold loves cars, his dog and everything Harley Davidson.*

*(Cleveland County)*

# WHY FUTURE PLANNING?

Future Planning is the preparation one does to ready themselves, their family and their estate for the time when they are no longer able to manage these parts of life - whether due to incapacitation, illness or death. All people could benefit from a plan for the future, but the recommendations in this report are specific to caregivers of persons living with an intellectual or developmental disability and/or traumatic brain injury.

Some key components of good Future Planning in this context include preparing a Letter of Intent explaining your wishes for your child, creating a will and plan for your estate, and creating a Special Needs Trust to administer and protect money left behind to benefit your child and protect his or her public benefits. Not everyone will need all these components so every family needs quality guidance to develop their own plan. Guardianship or alternatives to guardianship should also be considered.

Equally important in Future Planning is identifying or building a personalized network of support for a person with I/DD, drawing initially from current trusted relationships with friends and family and then growing the network with new people who emerge through shared interests or activities with the person with the disability. This network serves as a “safety net”, to support the individual and caregiver in the present and more importantly as the caregiver ages. Individual members of the network can even be identified to provide information and advice in specific areas such as finances or health. Such “supported decision making” is a kind of guidance that encourages self-determination. Personal networks are one of several alternatives to guardianship that are available options in North Carolina.

A 2012 study reported that 41% of the Baby Boomer generation (born 1946-1964) do not have a will. When polled as to why not, procrastination was cited as the biggest reason (34 percent), followed by feelings that it was unnecessary (22 percent) or too expensive (21 percent). (AARP, 2012)

Further, a 2008 survey by The Hartford Financial Services Group showed that roughly 62 percent of parents have no long-term care plan in place for their child living with a disability and that 58% have their child identified as a beneficiary to their financial assets, something which could jeopardize critical government benefits and services. (Bankrate, 2014)

More research as to the barriers preventing aging caregivers of individuals with I/DD or TBI from participating in Future Planning is needed. It is clear that reluctance towards Future Planning transcends socioeconomic barriers, therefore it is important to find out what specifically is keeping many NC families from taking critical planning steps.



# COMING OF AGE STAFF AND TASKFORCE

*Betsy MacMichael*  
*Executive Director*  
*First In Families of North Carolina*  
*betsym@fifnc.org*

*Debby Torres*  
*Project Director, Family Support Coming of Age*  
*First In Families of North Carolina*  
*dtorres@fifnc.org*

---

## FAMILY SUPPORT: COMING OF AGE TASKFORCE

---

*Heather Burkhardt*  
*NC Division of Aging and Adult Services*  
*(Raleigh)*

*Gwen Phillips*  
*Chatham-Orange Community Resource Connections*  
*(Hillsborough)*

*Tonya Cedars*  
*Eastern Carolina Area Agency on Aging*  
*(New Bern)*

*Susan Reed*  
*Wake County Community Resource Connections*  
*(Raleigh)*

*Anna Cunningham*  
*Parent/Caregiver*  
*(Raleigh)*

*Ellen Russell*  
*The Arc of NC*  
*(Raleigh)*

*Kenneth Greenberg*  
*Parent/Caregiver*  
*(Charlotte)*

*Kathryn Sticksel*  
*OE Enterprises*  
*(Hillsborough)*

*Colleen Kilsheimer*  
*Parent/Caregiver*  
*(Durham)*

*Valerie Vizena*  
*The Enrichment Center*  
*(Winston-Salem)*

*Karen Luken*  
*NC Office on Disability and Health*  
*(Chapel Hill)*

*Janice White*  
*NC Division of Mental Health, Developmental*  
*Disabilities and Substance Abuse Services*  
*(Raleigh)*

*Joan Pellettier*  
*Triangle J Area Agency on Aging*  
*(Durham)*

*With special thanks to Marian Hartman*

---

## Works Cited

- Braddock, D. (2013). *The State of the States in Developmental Disabilities: 2013: The Great Recession and its Aftermath*. Washington, D.C.: American Association on Intellectual Developmental Disabilities.
- First In Families of North Carolina. (2012). *Survey on Family Support for Aging Caregivers to Individuals with I/DD*. Durham, NC.
- Heller, T. (2014). *Family Support In Managed Long-Term Services and Support in North Carolina*. Institute on Disability and Human Development. Chicago: University of Illinois at Chicago.
- Thaler, N. (2011). *Partnering with Families to Build a Sustainable Futures*. North Carolina Council on Community Programs. Pinehurst, NC.
- The Council on Quality and Leadership. (2000). *Personal Outcome Measures*. Towson, MD: The Council.
- Wingspread Family Support Summit. (2013). *Building a National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities*. Racine, WI: Building a National Agenda for Supporting Families .