CREATIVE USES OF NATURAL SUPPORTS

HELPING MORE PEOPLE, BETTER & BUILDING MORE INCLUSIVE COMMUNITIES

First In Families of North Carolina
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Partners Health Summit:
Whole Person Integrated Care

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The FIFNC MISSION
We exist as a catalyst for people with disabilities and their families in NC to meet their self-determined needs by leveraging relationships and resources, and encouraging reciprocity in their communities.
TODAY’S CONVERSATION

✓ Natural Supports defined
✓ The current Context: a true Mandate for natural supports
✓ Various peer support models currently available
✓ First In Families’ several uses of natural supports
✓ Community Time Banking
✓ Case study

The use of natural supports as a complement or substitute for formal services can benefit individual and family health, build greater awareness, and support more inclusive communities.
A LESSON IN SURVIVING
JANIE 20 YEARS LATER
WHAT DO WE MEAN BY NATURAL SUPPORTS?

✓ The relationships that occur in everyday life.
✓ An approach, not a service.
✓ When formal services exist: natural supports can complement and enhance them.

How?
SERVICES VS. NATURAL SUPPORTS

Formal supports may = safety, medical services, therapies, personal-care, & skill-building but:

- Are not intended primarily to connect people to the community; in fact can be isolating
- Are not primarily for relationship-building
- Do not always promote maximum independence

Natural supports can bridge the gap to support Social Determinants of Health.
NATURAL SUPPORTS AS A BRIDGE

Essential for the many people who have NO formal supports:

- Registry of unmet needs (>9,000 in NC)
- Services lost due to funding cuts or change in eligibility
- Helps people completely off the radar
THE MANDATE FOR NATURAL SUPPORTS

Current Realities and Policy Trends

Demographic Shift – Aging Baby Boomers
THE MANDATE FOR NATURAL SUPPORTS

Current Realities and Policy Trends

Too Few Workers to Care for Baby Boomers

Source: U.S. Census Bureau, Population Division, Interim State Population Projections, 2005

Larson, Edelstein, 2006

NASDDDS
National Association of State Directors of Developmental Disabilities Services
THE MANDATE FOR NATURAL SUPPORTS

Current Realities and Policy Trends

- Many family caregivers over age 55
People Living with Family

Residence of all IDD Service Recipients 1998 to 2009

Arizona 85.6%
Calif. 70%
Florida 71%
Idaho 75%
N.J. 70%
S.C. 73%
N.C. 59.5%

Lakin et.al. RISP 2009 -UMinn.
FAMILY SUPPORT & NATURAL SUPPORTS

- 71% of all NC adults with I/DD or TBI live at home
- Supporting families crucial to high quality support of individuals (on aggregate)
- Not enough $ for services alone
WHERE DO YOU START?

PEOPLE:
Who does Jeffrey know? Friends, family
…start there & invite others
✓ Informal social gatherings help people get acquainted
But Mary doesn’t have anyone in her life:
✓ Where to start?
✓ What is Mary interested in?
SHARED INTERESTS BUILD BONDS
BONDS BETWEEN PEOPLE LEAD TO NETWORKS

PEOPLE, continued:

✓ From existing friends & family, or new friends with shared interests……..

✓ …….Build an informal network or a more formalized Network*

*Lifetime Connections at www.fifnc.org
THE VALUE OF NETWORKS

PEOPLE, continued:

A network can help people create their own Good Life

- Get where THEY want to go
- Be a link to needed goods and service
- Be less reliant on paid support
SPECIFIC TOOLS TO ACCESS NATURAL SUPPORTS

PEER SUPPORT INITIATIVES

✓ Personal Support Networks
✓ Supported Decision-making
✓ Sibling Leadership Network and others
PERSONAL SUPPORT NETWORKS

- **Volunteers** engage directly with the PWD to help with goals and provide specific assistance.

- Typically includes combination of friends, family, community members, and professionals.

- Some have formal services, but some do not.

*Lifetime Connections*

*a program of First In Families of North Carolina*
SUPPORTING PEOPLE NATURALLY

Personal Support Networks – who is in yours?

- Navigating life issues
- Understanding medical issues
- Understanding money issues
- Understanding legal issues
Supported Decision Making & Personal Support Networks

... a recognized best practice through which people with disabilities use friends, family members, and professionals to help them understand the situations and choices they face, so they may make their own decisions.

- Who will I live with?
- Need a 2nd opinion about surgery?
- Is this offer too good to be true?
SUPPORTED DECISION-MAKING

SDM Leads to Greater Self-Determination

People with greater self-determination are:

- Healthier… *potentially less money needed through system*
- More independent… *fewer formal services*
- More well-adjusted… *fewer mental health services*
- Better able to recognize and resist abuse… *fewer costly crisis interventions*
OTHER TYPES OF PEER SUPPORT

Sibling Leadership Network

- Adult siblings engaging with other sibs to offer:
  - Emotional support
  - Education & training
  - Leadership development

- NC SIBS - currently 82 engaged with 10 “leaders”

- Also Parent and Self-Advocate Groups
"My parents died. Their parents died. Their parents died... it runs in the family."
SUPPORTING FAMILIES TO PLAN FOR THE FUTURE

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.

A First In Families of North Carolina Initiative
Funded by the North Carolina Council on Developmental Disabilities.
FIF CHAPTERS – MOBILIZING NATURAL SUPPORTS

✓ Assist people of any age with I/DD or TBI and their families
✓ Approx 3,000 met applications annually since 1995
✓ Help people achieve short and long term goals, including:
  ✓ Goods & Services
  ✓ Training & Education
  ✓ Long-term Planning
✓ Not a Medicaid provider
  ✓ Customer-led, founded by families
Founded by families of people with disabilities who:

- Recognized abilities of families and resources of communities
- Wanted to help people with I/DD or TBI to live in regular neighborhoods and homes
- Believed leadership by families and self-advocates critically important to make community connections
Very grassroots chapters have local Management Teams & Resource Consultants

- Find businesses to provide discounts and donations; need gets met & public awareness broadened
- Raise money through fundraisers; 100% to families;
- Reciprocity by families served
FAMILIES ARE THE EXPERTS IN WHAT THEY NEED

How can we help you?

… “What we really need is car repair, and gas”

… “help us pay for the support worker to attend the Y with my child”

- Otherwise they stay home
EXPENDITURE OF PUBLIC $ ALWAYS “LAST RESORT”

Examples from approved applications this week:

✓ Replace moldy rug in mobile home (child with CF)
✓ Colostomy bags (19 yo SB)
✓ Towing + car repairs (g’mother caring for 1yo born addicted)
✓ Insoles for adult with autism to keep him walking + YMCA membership
✓ Bedbugs- it takes a village
TIME BANKING

WHAT IS IT?

✓ It has been around since the 1980’s and was started by Edgar Cahn.

✓ It is a community of people committed to supporting each other by giving and receiving.
1. **THE ASSET PERSPECTIVE** - all people have something to contribute;

2. **REDEFINING WORK** - need to notice what we take for granted around us;

3. **RECIPROCITY** - offer opportunities for everyone to be able to help others;

4. **COMMUNITY** - no more disinvesting in families, neighborhoods and communities;

5. **RESPECT** - each of us is entitled to respect—that boils down to equality
HOW DOES TIME BANKING WORK?

The basic idea is simple:

- One hour of service = One Time Dollar
- All hours of services are “valued” the same.
TIME BANKING IN ACTION

TIME BANKING
The Cycle of Sharing Time and Services Continues

- Michael paints the walls in Joanne's kitchen for two hours and earns 2 Time Dollars.
- Joanne spends her Time Dollars to get Spanish lessons from Maricruz, who earns 2 Time Dollars.
- Maricruz earns 1 more Time Dollar by giving Ha a ride to her doctor's appointment.
- Remington earns 3 Time Dollars by pet sitting for Karen.
- Ha earns 2 Time Dollars by giving Remington computer assistance.
NORTH STREET NEIGHBORHOOD
SONYA & JANIE
PERSON BY PERSON COMMUNITY GROWS
Be aware of specific needs that could be met by smart technology as a substitute for formal support:

- Cleaning
- Safety gadgets and fob opener doors
- ECHO and other voice activated devices
- Pill reminders
- Phones and phone apps
- Dogs and other animals
- Debit cards
SMART TECHNOLOGY AND APARTMENT LIVING
1. Seek existing **PEOPLE** or create new networks of people
2. Default to **COMMUNITY** living to greatest extent possible
3. **ENGAGE THE PERSON** themselves to lead the process
4. Utilize smart **TECHNOLOGY** to minimize unnecessary and isolating formal services and to maximize independence
SUMMARY: RESOURCES TO CONNECT TO NATURAL SUPPORTS

1. First In Families chapter support & future planning resources;
2. Lifetime Connections Personal Support Networks
3. NCSibs; and parent & self-advocacy groups
4. Community Time Bank
5. Community Guides; PCP through LME’s
CONCLUSIONS

- Majority of NC adults with I/DD or TBI live in unlicensed homes.
- Many kids and adults receive few or no formal services.
- Connection to natural supports vital due to “perfect storm” coming.
- Natural supports complement and enhance formal supports.
- Supporting people naturally builds community.
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