

VISIONS OF FAMILY SUPPORT

Statewide Conference

June 10-12, 2001
Jekyll Island, Georgia

Connie Lyle O'Brien and John O'Brien listened to about 50 parents at the conference. These notes summarize and organize the points that parents want to bring into the discussions that will define family support policies and practices in Georgia.

A MISSION FOR FAMILY SUPPORT

SUPPORTING FAMILIES
TO CREATE GREAT
MEMORIES



We need to look at the whole system of support a family relies on....

"Getting family support can be so difficult that
you just give up on it because
other family priorities matter more."

SCHOOLS that...

- don't listen
- exclude from regular education
- don't support and build on strategies that work for a person
- make it a lot of work to get what is needed
- resent advocacy
- resent parents' ideas and suggestions
- provide too little developmental support (OT, PT, Speech, etc.) & take it away when there is a little progress
- limit parents' work time by not providing summer or after-school alternatives
- treat autism as an emotional or behavioral disorder and try to put child on medication

The way services are provided can stress families

PROFESSIONALS who... (MD's, Psychologists, Teachers, etc.)

- lack knowledge & don't work to gain more... no continuing education required
- disrespect family
- have poor problem-solving skills
- disregard knowledge of families
- have turf problems with each other & can't, don't, or won't cooperate

FALLING OFF THE CLIFF at age 21

- No entitlement to services after public school
- Medical Assistance (MA) benefits decrease or go away

RESPIRE that...

- is hard to arrange
- can't accommodate family needs (like mother's surgery/recovery)
- is only available two hours drive away
- is on a "use it or lost it" basis, especially when it can't be used because the system fails to provide staff

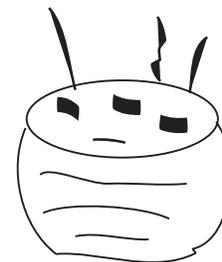
DISABILITY categories that...

- don't allow for individual difference, e.g., a person can be gifted + have learning disability + have Asperger's
- create ineligibilities that don't make sense; are not fair

Family Support is...

"FAMILY SUPPORT should start with family priorities, not just say, "This is what we have, so this is what you get."

like my chicken pie



*warm•satisfying•not complicated
a comfort to the soul
–Ruth Langevine*

Job description



By staff joy of living

laugh often

respect person for the whole & wonderful person they are
enjoy, encourage, assist as needed

Family Driven

- different for different families
- based on strengths, needs, culture, values of each family
- focused on the whole family
- directed by family decisions

Flexible

- families can choose based on own definition of needs & preferences
- focused on increasing opportunities
- changes as family needs, goals, roles, ages change

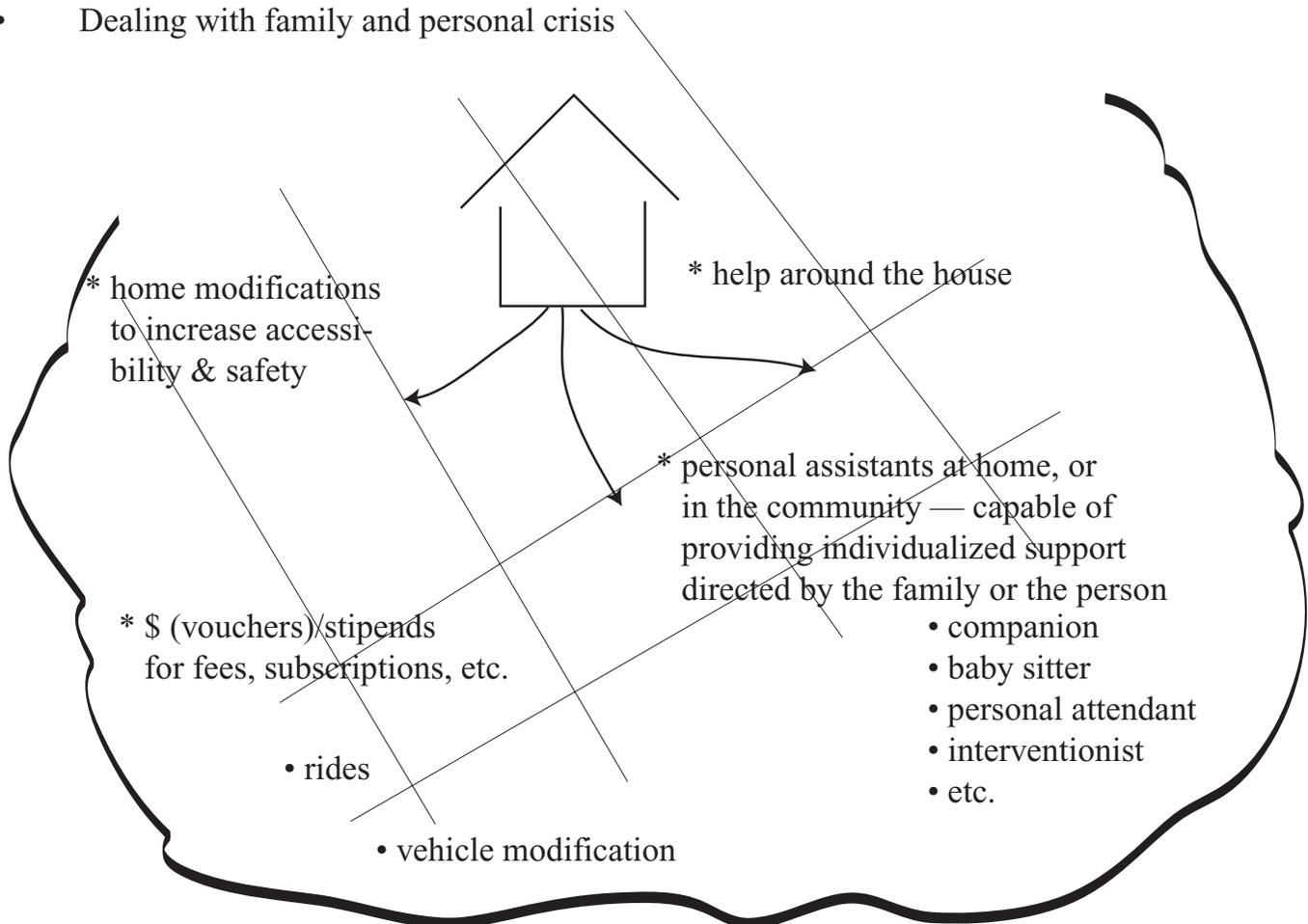
Easy to use

- minimum of paper work
- "How can we help you?" attitude from staff

MAKING DAY-TO-DAY LIFE BETTER

Provide skilled help with...

- Making a family plan for Now and Long Term... think about adult life for family member with a disability. What happens when parents are no longer able or available to help?
- Connecting to available resources: personal and community resources & service system resources
- Forming a support circle
- Figuring out how to make life at home in community better: decrease family tensions; learning to deal with difficult situations; making necessary medical/ personal care routines fit in more smoothly
- Dealing with family and personal crisis



Families have the option to direct how \$ is spent...

\$ Families (or groups of families) have the option to recruit, hire, train, their own support workers... and don't have to pay agency overheads if they do this themselves ... so they have more money to spend.

Sometimes this is too much for a particular family to manage, so the option to buy help with recruiting, hiring, etc., is also important.

Families can "bank" (some of) the resources they do not use.

Groups of families can pool resources.

\$ Provide vouchers.

\$ Change Georgia Medical Assistance (MA) rules to allow payments to family members up to Federal limits.

\$ Change Medical Assistance (MA) plan to include benefits to adult MA recipients: dental, PT, OT, Speech, & equipment & supplies after age 21.

\$ Provide sufficient wages to recruit + keep capable people to do the work.

- Hold down overhead.
- Pay fair wages & benefits.

\$ Families define what they need versus being told what they will get.

\$ Should there be family income limits on eligibility? Family budgets may not be sufficient to cover desirable supports.

\$ Families can purchase goods or services they believe will improve the life of both the person and the family (e.g., diets not covered by insurance; tutoring; intensive training, etc.).

Not just cash...

Encourage and support exchange networks

- *Family to family*
- *In the wider community*

— person-to -person support
 — the relief of understanding + being understood without having to explain, explain, explain

Opportunities to gather as:

- Dads
- Brothers & sisters
- Grandparents
- Self-advocates

- Building support with/ healing extended family
- "Extending" our family by choice

links to other families & adults with disabilities

- what might work...?
- what is possible...here... all over the world?
- what does the diagnosis mean?

information

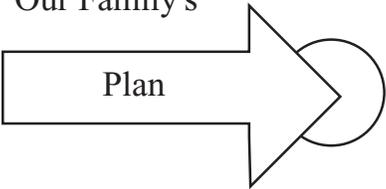
- what's available?
- what's happening that could help?

- Access to internet (dues & subscriptions)

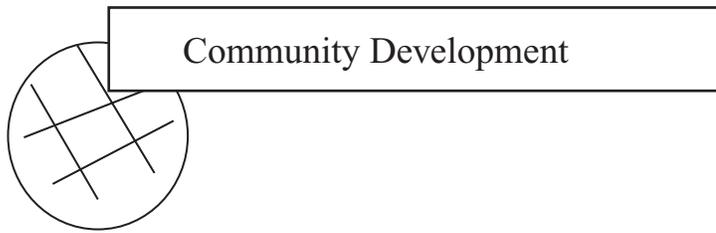
skills & knowledge

- planning & problem-solving
- what works for our family — our family vision
- how to get what's needed from schools, services
- how to get help from people & organizations in our community
- how to work for change in our community & our system

Our Family's



- what we need to thrive — a positive future
- how services can support us



- Increase the numbers of people who see support work as a rewarding job

- Increase the competence of workers
 - offer training by families and people with disabilities
 - offer training by agencies
 - local colleges and universities

- Increase accessibility + competency of local...
 - child care
 - recreation, summer programs
 - churches, synagogues, mosques
 - medical and dental care providers
 - family support services
 - housing/home improvement, home buying assistance
 - public transportation

The "grieving model" has been with us too long; it's incompatible with the disability rights movement.

I didn't realize how much potential there was in my son and how much potential there was for me growing in relationship to him.

Susan Yuan

Tough Questions

As Family support dollars increase...

... do we want to keep Family Support dollars separated by diagnosis?

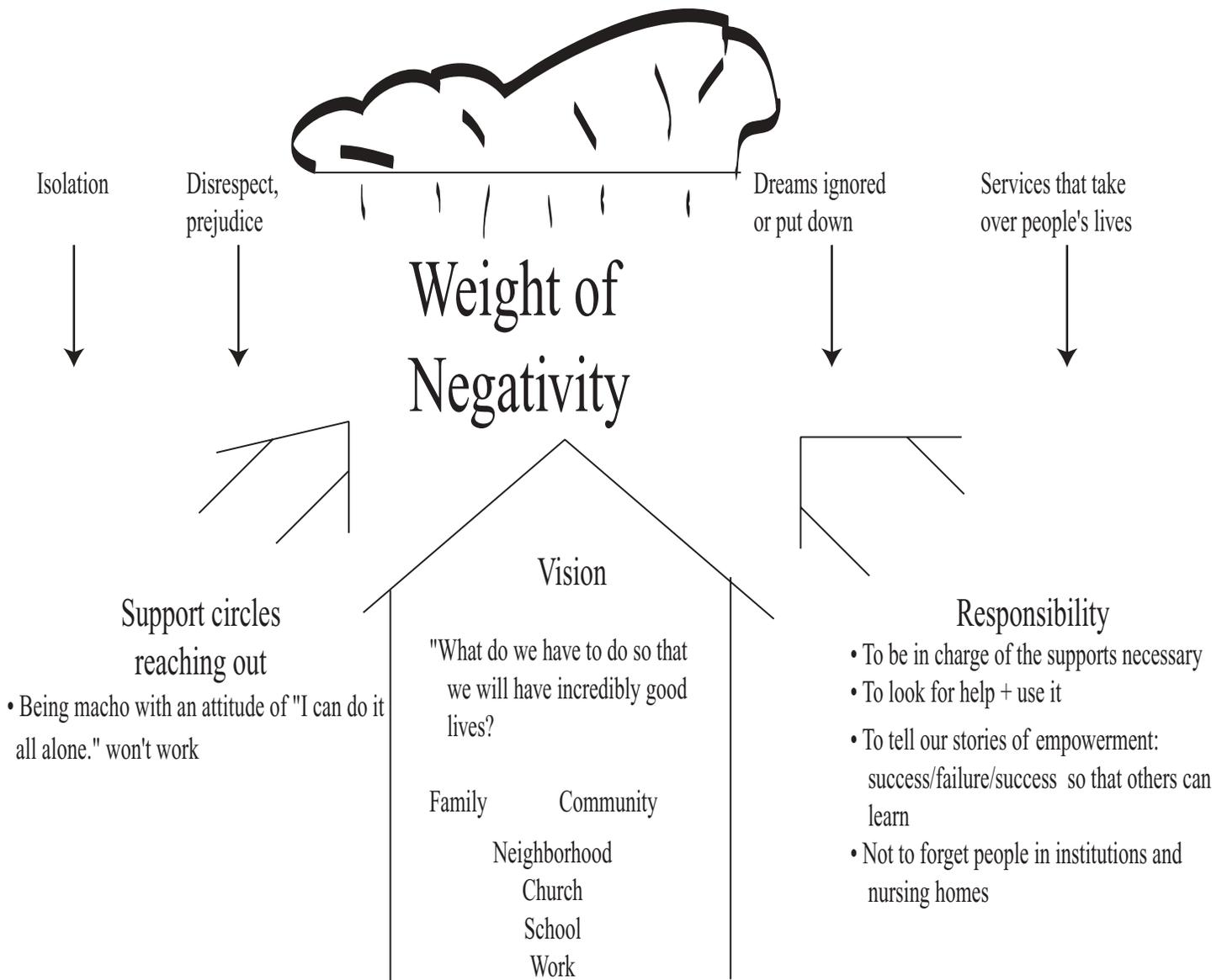
... if a family's highest priority is an intervention that could benefit their child, but it is not paid for (or is denied) by school, MA, insurance, or the DD system (e.g., ABA, special diets), should we advocate for this as Family Support or advocate for expansion of other services?

... when will we send families to other community resources rather than spend Family Support dollars? other personal resources (insurance or savings), other social resources?

... do regional differences in allocating money ever make sense?

... at what point does family support directed by the family shift to individual support directed by the person with a disability?

... what is a fair way to deal with built up demand that will get us out of the "wait for a crisis" cycle and into prevention of crisis?



Michael Long (1999). *When your dreams are big enough, the facts don't matter.*
 Order from bn.com for \$9.99.

Opportunities to learn and get involved

- Get on the Family Support listservs
For Georgia: <http://groups.yahoo.com/group/familysupporttalk.ga>

Get info: www.Familysupport-hsri.com
- Attend Family Support Training, become a trainer (there is money to support you to do this).
- Join the Family Support Policy Council
- Talk to your local Family Connections group
- Get organized regionally. Get to know your Regional Board. They control how money is spent.
- Get involved in "Unlock the Waiting List" campaign (1-877-924-8547).
- Don't call Charles!

Persuade through pride and passion

Look into your hearts



Change thinking

- Our children are NOT broken
- Our families are NOT broken
- Do not accept pity — go for respect
- Know what you know

Ask: How should it be? Then: Work to make it real.

If we can IMAGINE it
and we PUSH for it,
we will get it!

Don't be...

- limited by what we know now
- thinking "I am only a mom" (or dad, or brother, or sister).

Families are the
best educators for
policy makers.

— Fran Smith