

The Children's Freedom Initiative Summit

Sponsored by

The Georgia Advocacy Office
The Governor's Council on Developmental Disabilities
The Institute on Human Development and Disability
People First of Georgia
The Statewide Independent Living Council

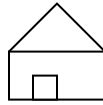
To make sure that children residing in congregate facilities live
with permanent loving families and that in the future no child will
be institutionalized

August 25-26, 2005

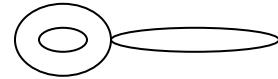


Children's Freedom Initiative
August 25-26, 2005

How Are The Children?



Bring HOME the Children



Need to Create a Stir

Let the children be

-happy
-safe
-well



....and have a permanent home
with a loving adult



Language and stories are Powerful!!!
Join us to tell the story in Georgia

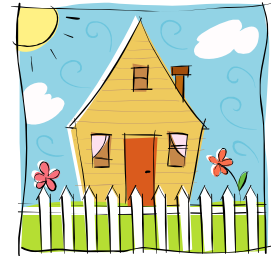


Families

- Set of virtues
- Commitment
- Persistent
- Loving



Longing for Home



- * Overcome Fears
 - * Impossible Choices
 - * Believe in Me
 - * Bearing Witness.....
- Not looking for a babysitter
Want someone to teach skills

Institutions are scary

Believe in self
Missing family

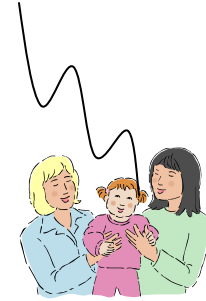
Giving a child over to DFCS is not for
a kid who has a family

The system considers you wealthy if you
make \$1200

I worried about her so
It felt like she was helpless
I couldn't find help
I can take care of her better
I know her needs
Now I have help 3 days / week

Harriet

Family.....Hanging By A Thread



My family had economic privilege...shouldn't have to be
We hired help which was really important
It liberated me...I wasn't dependent on my parents to do it all
My parents were busy
I helped direct things at home
I went to a "crippled" school that was separate from my siblings
I went to a camp where some of the campers came from an institution
....they weren't that different from me
I didn't ask about their lives....Maybe it was fear...maybe it was shame
There were no school programs for them
Sterilization was going on
Some people graduated from school to the institutions
Parents were aging and there were no options
I had terror in my heart....It could happen to anyone
Death.....Divorce.....\$ trouble

Help comes and goes, but family is consistent....Everyone contributed
They have expectations.....and give you connections to the community
Kids are forgotten if they are "put away"...need the ties that bind and connectedness
There needs to be more than respite...regular daily help should be available if needed
Don't force families to be poor.
Support Families of all kinds
De-medicalize support
Find alternate families if necessary.

Having a paid assistant was important
...I could tell them how I liked it
...I could be bossy
...It let me separate from my parents
...It can be hard to have an outsider in the house, but at least give that option

I have strongly protested the MDA Telethon over the years...had an article in NY Times
...It plays on pity
...It stereotypes people
...It views people with MDA as half a person
...It is insulting
...Disability is not about suffering

I was asked to be part of a discussion at Princeton University
The professor's view was that parents should have the legal right to kill their disabled child...He had pity not hatred....He only saw suffering...We need people to see the Value of Life...Mainstream views can be distressing...There are lots of reactions to disability...We need the view of suffering changed....It can be a life or death issue.



POPCORN

Pam Need outreach so people know about the services like the GAPP program
Need good supports in the home so families don't fall apart
 ----stress ----financial impact, bankruptcy
Make it a healthy home for the entire family
Parents learn the care or their kid is in the hospital
24 hour care....you need the help....need to beef up services

Laurie My son is in a nursing home....He has been there for 6 years
I want a chance for him to come home
That is where he needs to be
I need support to be able to bring him home
There has to be some way to get him home. It is a MUST !!!

Dr. Lowell Clark Medical supports can be few and far between in rural areas
There is a default because of no services
Kids end up in the most expensive option (Pediatric ICU)
ICU isn't appropriate...it is a precious resource
There are a limited number of pediatric ICU beds in Georgia
I didn't know there were kids in nursing homes
Need attention to simple things....like care of feeding tubes.
Nursing home docs aren't pediatricians nor specialists in disability
You don't need nurses to do 80% of the supports
But Medicaid doesn't pay for less than nurses to do the care

Lisa I have a 14 year old son who has cerebral palsy
He is growing and it is hard for me to lift him
I never want him in an institution
I will need help to keep him at home
I work in the field and don't know where to go for help
We need to make sure that parents get training
I had to learn how to give my child shots...must have proper training

Josh About half the kids we are talking about are in private facilities
And half are in state facilities...About 70 are in nursing homes
There are about 142 kids total in institutions or nursing homes in GA

Paula My daughter's care was a full time job
Dealing with the school was a full time job
She was "in there"
We economically collapsed as a family
We needed enough people around, but it is difficult to sustain
Listen to families...needs will be different...one size doesn't fit all

Jerilyn We need to do a better job helping people understand services.
We need to educate churches and let them know the needs
so that we broaden the circles of support for people.



Vicky It is a challenge to get kids out of medical settings.
It is hard to keep nursing services in place over time.
We were serving a child who needed 24 hour care and suctioning.
She had a wonderful personality and had lots of fun.
She communicates...The system spends much more for her to be in
the hospital...it would cost less to pay for the nursing in her home.



The system is designed for services to go away, but the needs don't go away

Kisha I was told to give my child up to the state
If in DFCS custody...he would get help.
I was also told to have my son arrested.
The system is BAD
Parents just want help!!!
You have to PUSH....PUSH...PUSH and play politics

Bernard My friend Teresa died recently
She fought hard to get out of a nursing home
She didn't give up
I'll fight for kids not to be put away.
Teresa was self-determined
We want kids included in the community
Parents must get the support they need.

It is important for people to live their dreams until they die.
My friend Leonard did that. He loved music and was a DJ until the end.
We struggle to get the medical help that we need to stay in the community.

Bruce The GAPP program reduces the nursing hours.
They gradually reduce the hours & the family takes over
Your reward for taking good care of your child is a reduction of services.
They need to re-look at it.
When nursing hours decrease...the chance for hospitalization increases
and is more costly...They need to stop punishing parents who take care of
their kids

Lynnette The Nurse Practice Act is a barrier.
....need changes in it and in licensing laws

Tamika How do you find out about the GAPP Program?
 And how do you access it?
 Who is eligible? DFCS doesn't know

 May contact a nursing agency who could help
 Child must meet the level of care
 The MD determines
 It is a tedious process

Tammy I admire and respect the families.
 My parents are advised not to bring my sister home.
 They did...She has had a good quality of life.
 People need basic supports.
 It is disgusting that we are still having that discussion.

Terry My son has 14 doctors who work together.
 He has a 28 page medical history
 But Christian is FULL of LIFE!!!!



Dr Rubin Doctors have a limited view.
 They are trying to understand.
 We are learning all the time.
 We do better when we all work together.
 None of us exists in isolation...we all need support

 There was a young man (D.K).
 I learned a lot from him.
 He is age 15 now and lives at home.
 His dad is a contractor...that helps
 He has lots of medical conditions
 Many specialists treat him
 It can also lead to additional problems

 Need primary health care
 Need to prevent secondary conditions (therapies)
 Need coordination of care
 Need education

 Want knowledgeable and experienced providers.
 There is so much to know
 Want a system that supports both the child and the family

Dr Rubin

There are problems because of limited training and limited knowledge of resources.

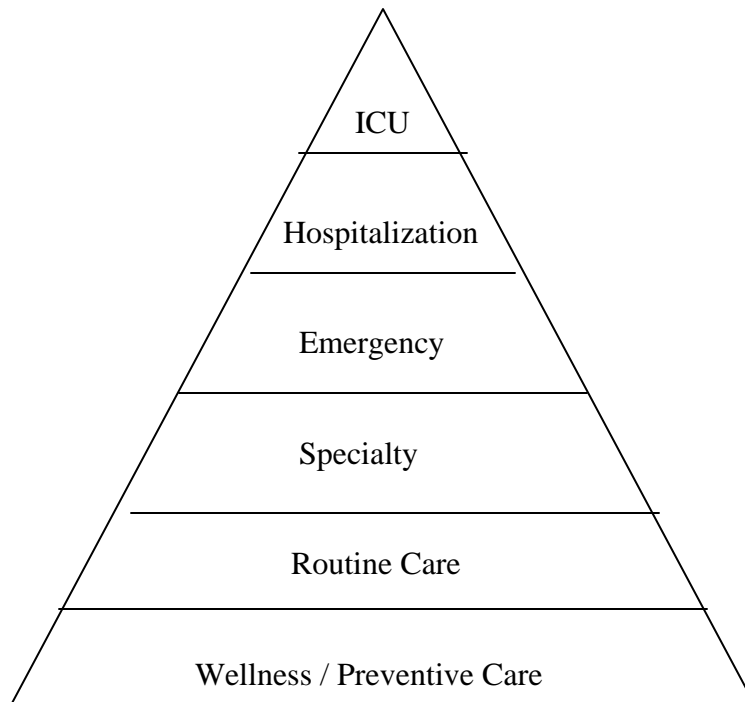
The medical profession focuses on acute problems and not on folks with chronic or multiple conditions

Managed care...limits providers
That is the opposite of what is needed

The solutions are simple.
Improve TRAINING,
COMMUNICATION,
AND COORDINATION

Project DOCC: is a training program
Funded by the DD Council initially.
It gives residents an intern experience in
Developmental Behavioral issues
...visit homes
...see how they deal with day to day life
...interview parents
...participate in grand rounds

Health Care for us all...Must advocate for improved systems



MEDICAL HOME

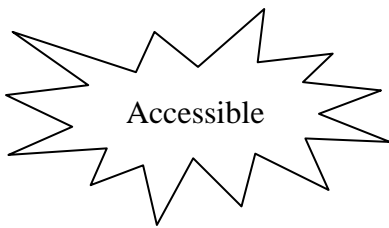
It is not a place...it is an approach

- health care
- immunizations
- behavioral health
- chronic health problems
- cognitive evaluations (how they learn)
- medical equipment

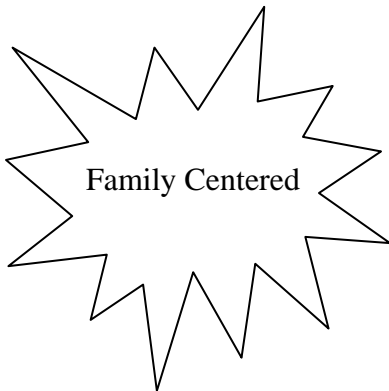
It is a multi-discipline approach
 Coordination – team approach
 High quality care

Continuous wellness
 Illness
 Awareness of change

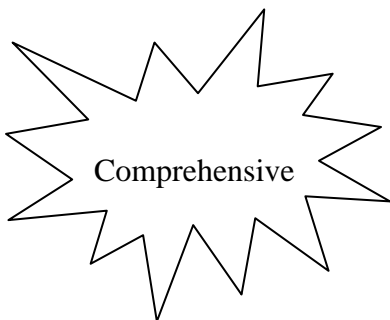
Kids fall through the cracks – transition times



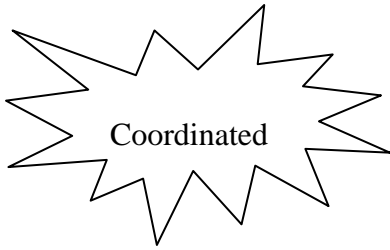
The Building
 Schedules....after work hours offered
 Availability...by phone, too.
 Geographically
 Financially...insurance co. aren't our best friends



Collaboration
 Honor diversity
 Recognize strengths
 Share info
 Incorporate developmental needs

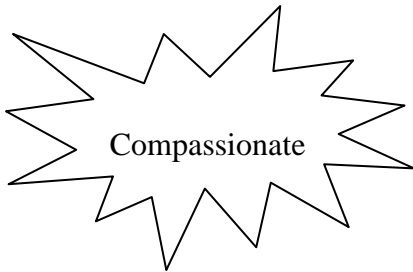


Care available at ALL times
 Promote.....HEALTH
 INJURY PREVENTION
 SPECIALTY HEALTH CARE
 COORDINATION



Is challenging
E-mail works well

Links with other professionals and family
Information shared
Central Source of information
Coordinated care and services
Persistence in trying to figure out problem/solution



To the family...the child....and the caregivers
Listen
Identify priorities



Cross culture communication
Respect backgrounds

Dr. Clark

The world is gray

ICU is the most expensive

Airway issues – oxygen to the brain
Is Life or Death....no B.S.

.....not warm and fuzzy

....hard edge

....that is why they are in ICU



Need to address end of life issues....people avoid talking about the possibility of death. Many families have been told that their kid won't live long...not so anymore...Breathing and feeding holes can prolong life a long time

Foster kids.....It is a social issue
Question of custody versus parental rights
Medical professionals need procedure permission
Decisions about resuscitation and end of life
...DFCS skirts the issue
...They say do everything
...That is not always the best
...People can die with dignity

Finding a home can be hard as some kids are so fragile
PICU is multi-disciplined...a precious resource & very expensive.
There are overwhelming responsibilities

Don't send kids to a dysfunctional system.
The best home is one where they are highly motivated and willing to learn the skilled care

Central State Hospital nursing home is an option now.
Some kids get in bad shape even if living in a loving home



We need transition / halfway homes for medically fragile kids.
The community is not ready.
It would give a place to train families.
And would be a place where kids have access to a pediatrician



We need alternatives.....WHERE YOU NEED THEM
.....WHEN YOU NEED THEM

Creating Family can be both a dilemma and a solution
Our alternatives are around what we have and what we know

Karl

Child Kind is an agency that serves 71 medically fragile kids
We use family foster homes.
Recruitment is the hardest element.
We want to match kids with the right family
We want people who are well trained.
We want to be the BEST.
In the past 16 years, 400 kids have been through their program.
It is a unique population.

The have a Bridge Coalition.
The customers are the foster families
There are 7 non-profit agencies who are partners
They provide wrap around supports
This might be for respite care or for specialized equipment.

Foster parents recruit other foster parents.
Being a foster parent often leads to becoming an adoptive parent.
We try to nurture our foster parents.
We have a “Date Night” where we care for the kids so they can go
out...we partner with restaurants and places of
entertainment

We work with Children’s Health Care of Atlanta
It is hard to get kids out
We have foster parents in the “pipeline”
There is often DFCS involvement – we want to be their
best friend by providing great foster families
The relationship with Children’s Health Care of Atlanta
has given added training opportunities and pre-service
training



There needs to be an in-between transition option
between the hospital and the home
It would be a place where training on the care could occur
and a place where kids would receive the appropriate supports

Terry

I’m against institutions
I’m an RN
My son, Christian, was the best thing that ever happened to me.
Our children belong in loving families.
There is no one on one manual of how to do it.

Christian has MANY medical issues.
He has had 90 surgeries....We deal with it
His body systems try to compensate and are weakened.

As a mom, I deal with it by being well organized.
I don't take NO for an answer.
I ask WHY? and WHAT CAN I DO?

His neonatologist said not to take him home.
I didn't see him the first 3 days.
He was only given days to live, but he did.
It is a fight....It is not easy.

DFCS said I wasn't a good mom.
They had him for two years.
They wouldn't give me the resources to help my son.
I was constantly scrutinized
They keep his case open....I'm not sure why.
Service agencies dropped him.

They paid \$2600 a day for two weeks for his care.
SOURCE is a new program.
Christian was one of the first to receive the services.
It is working...It gives families the help that they need.
We pool our resources and share information.

He can have 12 hours of support a day.
He has suffered many times at the hands of a nurse.
Give me the hours when I need them.
He is approved for 84 hours, but I only use 56 hours.

Let your legislators know...the system can work.
There are lots of loop holes.

I'll never have him in an institution.
Christian has a four wheeler...he rides on a tractor
goes on boat rides and plays the drums
That is LIVING for Christian



Network resources
Relationships are important.
Families need a break.
The person needs relationships beyond their family.

I know my child's needs.
Doctor's respect me.
I keep up with the details of his needs and care

Tammy

Using Medicaid for Non-Institutional Services

I work with Bazelon and I'm willing to provide technical Assistance in Georgia.

Medicaid is an entitlement
Each state has state plan that is different.
All services aren't federally mandated
It is like a menu and they can pick and choose

Eligibility....low income people
.....kids with disabilities
(SSI, MAO, institutionalized more than 30 days)

It is a stable funding source and extends what states can do.
There have been budget cuts
Now people look for what Medicaid will pay for
not for what people need

A Dilemma is LOST kids
....ones who are not Medicaid eligible
....ones who have no insurance or insurance is used up
....or kids with mental health needs

Availability of Resources?

EPSDT (early periodic screening, diagnosis and treatment)
Is a legal requirement not a program
Must be "medically necessary"
Can be covered even if it is not in the state Medicaid plan.
It is the LAW!!!!

The Alabama Foster Care went from the worst to the top 10
They give the supports needed

Rehab Option – can be creative...must use the right language
to get things funded

Can provide in-home support
Can be recommended by licensed practitioners other than MDs
There are existing codes so it is not debatable
Medicaid can be conservative.

We need to expand the eligibility for

- Home and Community Based Waivers
- TEFRA – Katie Beckett Waivers
(GA has been one of the top 10 states in using it)
20 states have it in their state plan
GA doesn't use it for kids with emotional/behavioral
issues....Target It....It is allowed federally

Dottie

Family Support is one of the best ways to make sure that kids don't have to be in an out of home placement. Seventy-five to eighty per cent of people with disabilities live with their families.


In the mid 80's we had a Search Conference and brought together service providers, state office personnel, and the office of planning and budget. The providers talked about all the things they were doing that were working well. It got comical because everything that was creative and making a difference was done "under cover". For example, there was money to pay for respite care, but not for a speech evaluation. So you might get a speech therapist to provide the respite care and while they were together, a speech evaluation might occur. The office of planning and budget said they would rather people call it what it was. Service providers agreed that it would be easier that way. The idea of Family support came from that conference. It was seen as a way to delay or prevent the need for out of home placement. Three areas of the state piloted the concept. The state requested \$50,000 for each pilot area. OPB understood the value and the cost savings that could come from this type of approach and they gave \$100,000 per pilot area. The maximum amount a family could receive was \$5000. Families weren't asked what you want to do with "your" \$5000...They were asked what would make a difference for their family. Most families that I worked with only asked for things that costs about \$1500 per year. They knew that other families also had needs. Some of the bureaucrats worried that families would abuse the money, but what we found was that families were just trying to survive. We had families who hadn't had a break in 20 years. We had single moms who were trying to hang on but it was difficult to work without reliable caregivers.

When we think about what it takes to get kids out of institutions and nursing homes, we need to be sure that we hold families hands and help them see what is possible. When we were planning for the kids to move out of Rivers Crossing, there was one mom who said, "I will kill myself, if you make my daughter leave." It really helped us understand how critical and urgent it was to listen to her concerns. She went through the person centered planning process and was given an opportunity to visit programs in the community. She saw that she

would be the one making the decisions about what her daughter's living arrangement would be like....where it was....who would be working with her daughter....what kind of furniture she would have...who might be her housemate. By the time she had helped design her daughter's supports, she insisted that her daughter be one of the first ones to move out. You can't just do a plan and not support the family through the process. There has to be a strong educational and support effort acknowledging what each parent needs.

One of my best teachers was a mom, Julia Nesbitt, whose daughter was sent to an institution in New Jersey when she was only 8 years old. The school system called trying to find an institution in Georgia for her. I went out and met the family and saw that they were in the process of building a ramp and an accessible bathroom on their house. It was clear that they wanted their daughter home. Julia was one of those mom's who might seem very negative. In meetings she would often tell us "NO" or say, "That won't work". I knew she wanted her daughter home so I learned to ask her different questions. I would ask, "What would it take for you to feel comfortable? The problem was that we had not paid close enough attention to the details that she knew it would take to support her daughter. She was able to tell us all the things that we needed to pay attention to for it to be successful.

The system added family support to the waiver through the Natural Support Enhancement Services. There need to be more resources targeted to support families. It is cost effective and can save the individual and family the trauma of an out of home placement. We also need to recognize that some people may eventually need out of home placement because families don't live forever. There isn't a family I know who doesn't worry daily about what will happen when they are not here any more to provide the care.



MORE POPCORN

Dr. Rubin PROJECT DOCC

- needs parent trainers
- work with pediatricians to help them be sensitive to families



Elaine My Big Learning was that the answers for how to get Donald home are embarrassingly easy...We know how to do this..... Why is he still there? I'll take this to OPB.

Why hasn't it happened?
...custody issue
...have to start all over finding the resources after 6 years
...need to learn more about resources
...need for care coordination
(get it in early intervention but not in education)
...can't be in several programs at the same time
...need someone to help families understand the system & issues

Tammy Case management is a service under EPSDT...Kids should be getting it!

Bernard Do we look for parents who have disabilities to be resources for these kids?

Vale DFCS doesn't discriminate against people with disabilities as potential foster parents...but we don't actively recruit them.



Pat P. As children get older
...have people with disabilities as role models...thru the independent living centers
...it can help parents learn not to be too overprotective

Glen What happens to the child if a parent dies...or they get divorced?

...There is no formula
...All families fear this
...DFCS

Steve Georgia has some of the best services and some of the worst.

Ideas for Alternatives

- living with friends they choose as they get older
- apartment living
- close relationships are important
 - ...citizen advocate
 - ...caring person
 - ...provider

Need to reduce the barriers so you don't have to fight to build relationships!!!
1:1 Friendships are important in life...It is not about case managers
Relationships make it happen... Seeing beyond disability to friendship
It works in small town, Georgia



Where are the CHURCHES?

It is hard for parents to keep asking and asking for help
How do we get the churches to own it?



Some churches are involved...Baptist Homes
Lutheran Services

Some churches are involved through institutions...They develop more institutions rather than reconnect people with the community. The churches are where there is social capital

Family attendance at church is lower for families who experience disability.
...families are tired.
...perception that the church can't handle the situation
...don't want another fight



Churches can develop small circles in their congregation
We ALL would benefit from circles
Beautiful things can happen
People will see the needs
I would rather have a circle than a case manager any day!!!



We need MORE COMMUNITY

Book: Building Community from the Inside Out

It can be done...it works.
There are people who want to help
But it isn't their life.



...we need to ask
...they may not know what is needed
...when they spend time with people, they get to know them better

We need to THINK DIFFERENTLY...LET'S LOOK AT THIS A DIFFERENT WAY!!

Discover talents of kids
Find a place they fit
Do neighborhood and community organizing

People need transportation
As people transition...they don't just want services
They want ORDINARY life things, too.

John O'Brien is a great GA resource who is under-used in this state.

Need a small town concept
...dinner and a movie
...a social life and friends
...it is hard to keep it going



Where are the CORPORATIONS?

DON'T MOVE RESPONSIBILITY AWAY FROM SOCIETY

It is a Right

Day 2 of the Children's Freedom Initiative

Eric J. Pleasure to introduce DHR Commissioner, B.J. Walker

DHR Values fit in with what we want to do for the kids

- community
- independence
- real jobs
- sustain and support families

B.J. Important part of who she is....grandmother to 4 grandkids



We share values
Want you to trust in us as partners

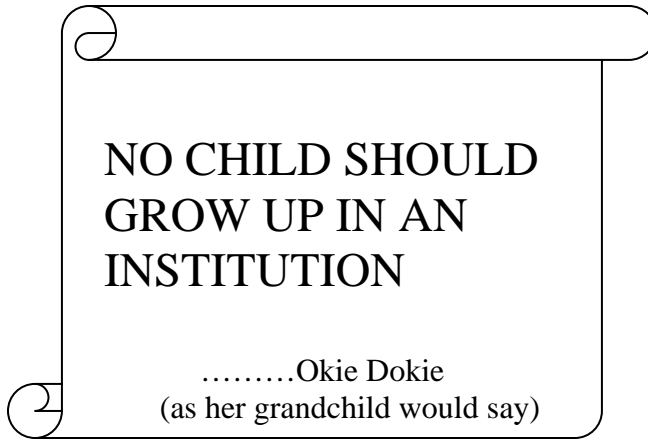
What will I say?
What will I do?
What are WE going to do in communities all around Georgia?

I want to share your ideas with others
...staff
...legislators
...children's cabinet

We have who we need to make it happen.

It will **NEVER** be OK for Georgia to be 50th !!!

All kids need to be able to participate in community



Georgia history has a bias toward institutions
We spent \$300 million last year for institutional services.
Georgia uses institutions at 3 times the rate of other states.

There was a man who was at Central State Hospital who died at age 99.
He was admitted to the facility when he was age 17.
The state spent NINE MILLION dollars on his services.
\$100,000 per year.
We could have bought him a house...a van...a nurse....and had money left over

What did he miss? A chance to work....to love....to see kids play...to live fully

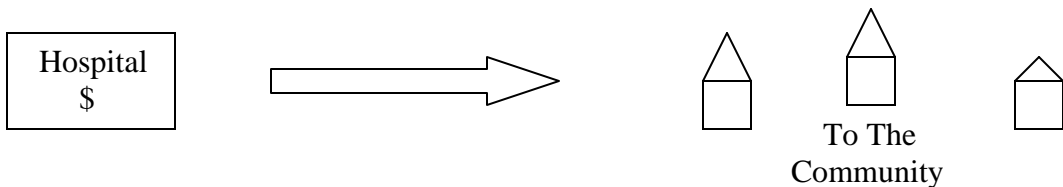
What talents did we lose?

What did it feel like to go in at age 17?

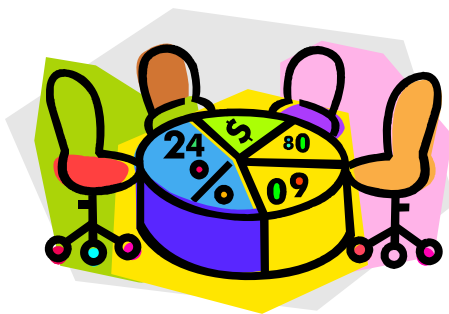
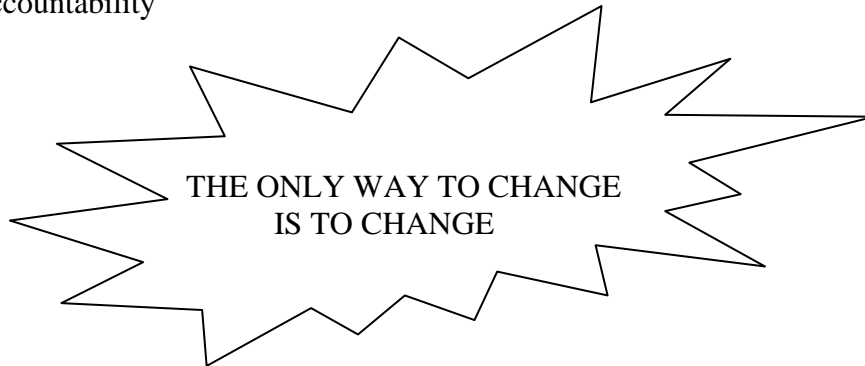
Let's never forget the NINE MILLION DOLLAR MAN

Our choice is to do what is EASY versus doing what is RIGHT
It is easy to just do the same thing
Doing the right thing may be hard

CHANGE among us is the RIGHT thing
Status Quo is NOT OKAY



Want continuity for kids
Want evidenced based practices
Need Accountability



Will have to take things off the table

To move people to the community
To address the 6000 person waiting list

Expand the waivers....925 this year...was unprecedented
Only had 20 the year before

The Governor believes that people belong with their families in the community!

The '07 Budget Proposal

Asking to add 1500 waiver slots
254 for people in hospitals
50 for kids in institutions
Many for people on the waiting list

We need to look for support to families
....aging caregivers
....for students graduating from high school

New Resources

Convert money from the hospitals to the community
Invest in the RIGHT work
Could serve 4 times the people in the community

Will we need more money?
It would be good
But we should do the right thing with the money that we have



Looking to help 19 people who have dual diagnoses move out of the hospital in Rome and 100 people in the Allen Building at Central State Hospital move to the community

We have aligned the regions and boundaries which should be good for kids

Need to be OUTCOME focused

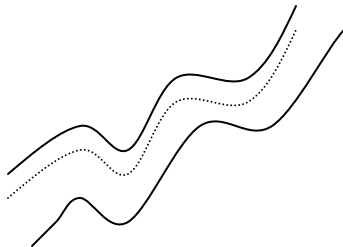
We need to provide CORE Services....and understand the customer

We are looking at a fee for services
Competition and Accountability

The Child and Adolescent Budget has been increased by 1/3
We want to invest in kids

There is an RFP – to equalize services across Georgia
We want to avoid duplication administratively and put the money into programs/services

We have “genius” leadership with Gwen Skinner and Steve Hall



They walk on the road....It is about people getting
What they need....whoever they are

We want people to be as independent as possible

- ☆ Flexibility
- ☆ Autonomy
- ☆ Work...Connects people to community
- ☆ Contribution
- ☆ Self Determination
- ☆ Independence



These unite DHR...It is the core that is fundamental

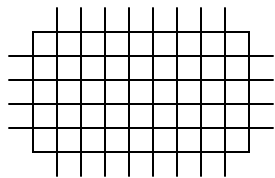
I know you are going to watch us like a hawk

We will reinvest the money into DD Services in the Community.
There is a credibility gap in DHR...We are working to turn that around


We will do what we say....And tell you when we can't do something

I promise HONESTY and TRANSPARENCY
It is a commitment

Call the Question....Can the community deliver?
Can they absorb the 1500 waivers? Need you talking to the community
Communities can shut down....Get them ready



There won't be a safety net if the community is not ready

It takes a village  not a hospital to raise a child

Families and the people we serve deserve more

What would you want us to do if it were your family member?

Proximity of family is CRITICAL in who we are
Take that value to the streets

Ruby M. There is a difference between community and community services
I'm glad to know that Commissioner Walker is a grandmother...

We would do well to think how our grandmothers might approach this effort

We need to think about the 1500 PEOPLE coming to the community and let B.J. worry about the waiver slots

We need to engage citizens of Georgia.
They don't know there are 3 year olds living in institutions.
People want to help

We need to do it 1 person at a time.

Great to have Nancy to share her wisdom with us
She has led the USA in helping people have individual supports
She has helped people move to the community
She is BRILLIANT

Nancy

What does the system need to do to support children in permanent loving families?

ACTION....not just a list of things

Some kids have families....some kids will need families
These are principles for human beings

DO WHATEVER IT TAKES

I'll tell you about nurses, nuns, pirates, and wallpaper
and how they made it happen in Michigan

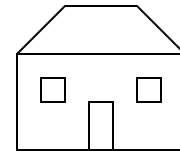
I sense a burning at the SUMMIT similar to Macomb Oakland
in the 70's

The Irreducible Need of Childhood

- Safe Secure Environment
- Loving, stable, predictable relationship with an adult
Who has the means and time to carry out the commitment

For a child, knowing that their personhood brings delight is a developmental imperative

In Michigan, we avoided group homes
and went for families



It wasn't about Freedom & Independence
Kids need dependence...someone they can count on

RELATIONSHIP

Was the Fundamental Piece

First Phase was the Institutional EXITIt has to be more than that...TO WHAT?

Permanency Planning

Change agents were state workers...individual, charismatic leadership



12,000 people who were in hospitals
1000 people in nursing homes

How to do it?
We decided to find families for them

We assumed their families couldn't do it since they had placed them
This assumption led to a birth family rebellion
But it created leverage for later developing birth family support

We provided \$\$\$\$\$- cash
 Services
 Practical help
 Emergency # to call if needed

The Birth Families said, "Give that same support to us!!!"

Methodology



Personal Ownership

Inspiration



to keep it alive

Make conversions in People....Make them believe its possible

Organizational culture

LESSONS LEARNED

1. We did it from the INSIDE OUT

Needed insiders from the "bowels" of the bureaucracy...needed them to figure out the "how to" mechanics

2. Pare it down to size so it is DOABLE

Some people might be able to help one person
Others might help more people move...they need to or it wouldn't get done

3. Find out WHO THE KIDS ARE

Started with kids in the state institutions.
Assigned it...Get to know each child and their family
Report....to the Director

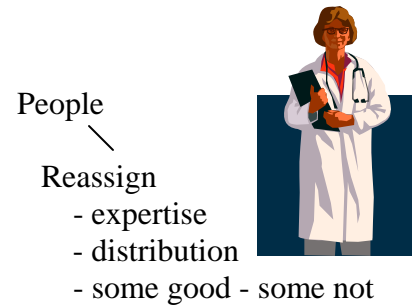
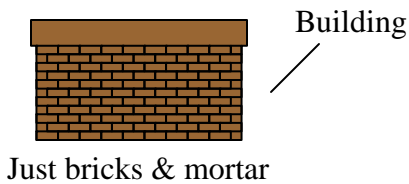
Remove the ANONYMITY....Make them REAL
Director had a list of all the kids on her door...checked off who moved daily
Questioned if there was not movement

4. CONNECTION – Worker Bees and Leadership

Expect and Demand

5. LOGISTICAL TASKS.....Re-deploy them

Deconstructing the idea of the institution



6. JUST DO IT



A nun and a nurse figured out how to move kids out....1 at a time

Create Stories

Christopher had a trach and needed suctioning.
Found a nurse who lived down the block
Would do it for less if paid directly
Couldn't afford to pay for a full time nurse
@ \$60/hr...nurses pay + the agency overhead
Was a WIN-WIN for everyone

Birth families said, "Show me the Money"
They said, "You give the money to other people"



The bureaucracy was not set up to do that

-slipped them in as foster families
-demonstrate the idea
-it saved money...and kids were doing well
-made it evidenced based
-do a demonstration project (gave same \$ except room and board)
-had the full range in how to use the money
-asked people to report to us how the money was spent

One family used the money to pay for wallpapering the house
They had lots of extended family who came together for meals
Their son, Anthony, could be deconstructive

- ...would unravel carpet
- ...would look inside the cushions
- ...would peel the wallpaper

They felt uncomfortable inviting the family over
Weren't able to be reciprocal and their world was shrinking
After wallpapering...they invited people back into his life

Found that surrounding families with what they need was not harder
than staffing a facility

Found that families were Frugal and Creative

Have to acknowledge that some kids are **HARD**
We had to be creative, too
Had to be **RESPONSIVE**

Chance for agencies to reinvent themselves
Developed a pool of support people to deploy

- ...when and where families needed them
- ...directed by families

Not to replace what families do...but to supplement

Some kids are **NOT WANTED**
Needed families to let them go
Don't put Parent Rights above the Child's Rights



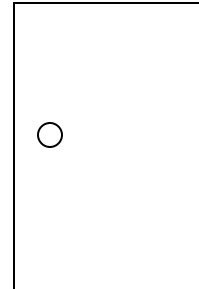
Some families desperately want the child, but can't
Need to create SHARED PARENTING

- ...Birth family reserves their rights...and maintains family attachment
- ...Might look within the extended family or invent a family
- ...Extended family can get worn out, too, and the family stop asking for the support...paying them for their efforts fixes that issue
- ...Way to approximate family life systematically

Some people will think that we can't find those families
There was a direct correlation between the number of people who came forward related to the amount of energy put into asking

7. **CLOSE THE FRONT DOOR**

- Recycle the Money to Families First
- Keep people from going in
- Tell some families NO to admission
 - ...don't abandon them
 - ...do permanency planning
- Offer the choice
 - ...support the family at home
 - ...choose another family to do it



HONOR.....Provide What is Needed

8. **HISTORY MATTERS**

- The longer kids are in a facility
- The fewer who will go home to their birth family

- 95% of families will never place their child in a facility

Plan a family life for those who can't go home

9. **DON'T ROMANTICIZE**

- It takes HARD WORK !
- ...tedious
- ...messy
- ...management by groping along
- ...it requires more than "All you need is Love"

10. CHALLENGE THE RULE BOUND BUREAUCRACY

It has to be intuitive
Can't do it by writing rules
Accountability has to be more than rules

Not just justice and fairness

Ethic of Care = Relationships

Little 5 year old boy wanted to play pirate

Little boy wanted to use the Justice / Fairness approach
And play pirate for 30 minutes
Then play neighbor for 30 minutes



Little 5 year old girl wanted to play neighbor

The little girl took the Relationship approach and said, "Let's play pirate that lives next door."

Georgia's Motto is "WISDOM, JUSTICE, and MODERATION"



Wisdom - We Need It
Justice - We Need More Than That
Moderation - We Don't Need That

Do what you can....When you can....Don't Wait to Figure it All Out

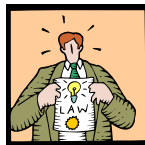
In Texas....passed permanency legislation....track every kid...every 6 months
....commissioner signs off on it

In Michigan....Did it through policy and practice....
Implemented an Idea

* A Newspaper Expose....didn't result in moves



* Law Suits



* Legislation

* Get someone on the Governor's speech writing staff

* Passed a Family Subsidy Bill so that money could go to families

* Relationships....is what really works

We weren't great at engaging the community
We invited families but didn't engage the community more broadly



In Michigan...we put ads in the paper...Work in you home for \$\$\$
Got lots of calls....BAD IDEA!



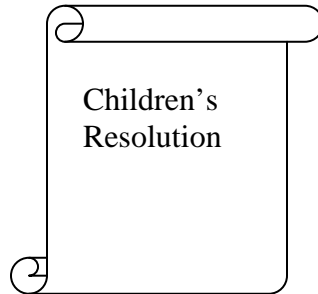
Attracted people to talk to
People's job was to answer the phone...they got a real person not a voice mail
Told them about the effort
Moved those staff out of the bureaucracy and into a house
Some applicants came back later...deciding that they did want to provide a home for a child.....May need an incubator period



Texas is really big....Local is hard....Our agency only has six people
Hard to reach out...Playing the angle of getting people who already work with the person
....aides at school bus drivers
Providers are also reinventing themselves

Representative
Judy Manning

- Plan...multi-year
- Move people to the community
- Identify action steps



Got It Passed

Pat Nobbie was the cheerleader for it



DD Community needs to get on the same page for the action steps
...responsibility
...advocate / family / self advocate roles
...department role

Ruby

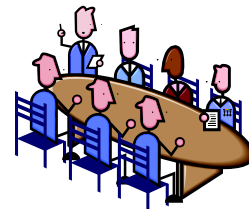
Be savvy about data

- o Others states are showing the evidence
- o What does Georgia want to buy?
- o Where will we put the support?

Pat N.

The Oversight Committee

- ...must be appointed
- ...low on priority list for the speaker
- ...might or might not be selected
- ...committee is determined to stay together regardless of appointments



Steve Engaging communities....Community organizing

...look at playgrounds
...are they accessible?
...make sure it is
...chance for kids to connect and play



Need models we can use....PR stories
Increase Awareness
Give trust to families
Expose the bias
Go back to lessons learned from the civil rights movement

Paula Educate the community – How to welcome people home

These are children....not objects

Humanize them

Change people's idea - that people should live in institutions



Nancy The family subsidy bill was initiated by six families

...they brought their kids with them to the hearings

...walk through what their day is like

...put a price tag with it

...became obvious...explained why they need \$\$\$

...it isn't paying families...figure out how to language it

Pat P. This is a very complex issue

When is it helpful and when is it harmful?

There are a large number of people with disabilities

When do you help and when do you not help?

Vale I liked the idea of families as foster families

...use \$ to support family

...do what makes sense

...do what is right without getting fired

Denise A big fear has always been of how the money is spent

Pooling \$\$\$

Other states are doing it...Ask how they did subsidizing families

Strategies for Engaging Communities

1. Tell personalized stories....with people's strengths and gifts
Tell them around kitchen tables with friends and neighbors
and in small faith based groups
2. Identify who are local people with credibility to do the asking
Know who the "movers and shakers" are in the community
3. Tap other kids as a resource to help figure this out
4. Develop a clear message....what are we asking?

Steve Hall

1 ½ % of all citizens on the planet have developmental disabilities...in any society at any time

So what are we going to do?

Create a Disability World or include them in Society?



Can we afford people who don't have severe disabilities?



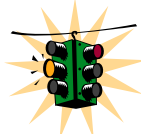
- Military expenses



Bridges / road -



- Libraries



Police Department -



- Tax Credits on Mortgages

That is Us!!!

Extraordinary is already going on
Multi-trillion \$ system that they
don't use

Where is theirs?

We provide support systems for
people now

Whether it be early intervention....school....or transition to adulthood

It is a myth that people are in different settings based on their level of disability

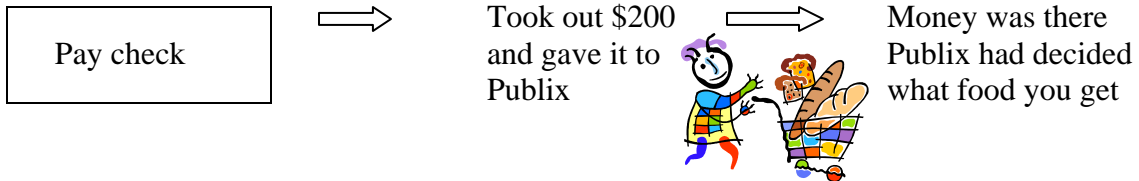
Research shows that the reasons why people are segregated and congregated are

1. attitude of the MD and family at the time of birth
2. which state you live in...dependent upon the local will

Assumption....People being where they should be with the supports they need

Get them the services and supports that they want

How the system is now: Other people decide the services that people get



If you look in the carts at the grocery store....you won't find any two that have the same items in them....We live in a democracy....People should have choices.

The new waiver....will provide for more choice.

- more family say so
- more services and support
- better outcomes
- should lower costs...other states doing it have hard data to prove it

It is a partnership...Not just families taking the money and running
It will take working together



There is a difference in Disability and Disease
We don't need the medical emphasis



It is not right for kids to be in facilities

What else may we decide can't be tolerated, too?

- boarding houses outside the system?
- Will find gross indifferences
- Waiting list – 14,000-15,000 people is probably more realistic based on the size of our state
- Adults in institutions who want out and staff agree...but they are still there

People with disabilities don't need to be "fixed"

Disability is a natural phenomena....people just need some support

Imagine if we took out the bridges in Atlanta for a day...they are just a support
What would happen?



We know how to do this stuff

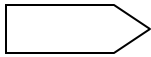
Retardation in meaningful interactions with typical folks

In the context of what people are doing, they may not be disabled
...shouldn't devalue people who take longer to learn
...it is the system who can't figure it out
...it is their perception that people have to "get ready"
...it is their perception, not reality

Pat N.- That is where the disconnect is....My daughter Mia had a job interview last week. The Human Resource person treated her like everybody else who applies for a job with them. The business is willing but needs some support...It is the 3 systems who can't figure how to do it.

Steve Hall - In the future 11% of people will have a child or a grandchild with disability...they will understand and accept it better because of knowing someone with a disability

Lisa - We need to change the way we talk and the language we use in helping people get jobs



Silver bullet How to Make it Happen? **JUST ASK !!!!**

Approached a clothes shop to ask if a young man could come and vacuum in the afternoon because he really wanted a job. Asked them to give it a try. If it works, Asked them to tell another employer...That generates new employers

If you want to approach a church.....ask the church secretary...they run the show. But approach them either on a Monday, Tuesday, or Wednesday.

We talked to a woman in a civic group...and she agreed to sponsor membership for a woman with disabilities.

Some employees in the facilities might move out and work in the community.

Some employees may also "scare" families and try to influence legislators so the facility does not close.

There is expertise that these employees have that we don't want to lose.

This whole Children's Freedom Initiative started when Gwen Skinner found out that there were kids in nursing homes and institutions. She was appalled and said lets fix it She spread the word....And people have run with it!!!

Eric J. Thanks to the Planning Group

- Jenny -Gillian -Josh -Dottie
- Mary -Katie -Pat N. -Pat P.
- Ruby -Zo -Eric -Glen
- Bernard -Dominique

Ruby, Zo, and Eric had been meeting at a hotel lobby when Steve came up. They were discussing what might be Georgia's response to the Alliance for Full Participation. They had asked Eric to pull together a team from Georgia to participate in the meeting in Washington, D.C. in September 2005. There are 30 people from GA who will be attending. They all wanted it to be a pressing issue. Kids in institutions and nursing homes fit that bill. When each of the partners talked with their colleagues about the initiative and the collaboration, other national organizations became interested in this issue as well.

It is like a 5 legged stool.....including people with disabilities, advocates, providers, families and legislators.

There is an oversight committee....We have all seen 19-20 studies done in GA with no results...We need this oversight body to "DOG IT" and report back on the status

We must work together....in the same direction
We must trust each other or the progress will STOP

We need to rethink
What we are doing
How we are doing it

Support can come in many ways
Talk to your neighbors....Tell the stories of kids



Do community development....welcoming ALL people



Margaret Wheatley says there is no limit to what can be done when we discover what we care about.

Commitment of resources over time of the DD Council, GAO, and IHDD



IDEAS FOR NEXT STEPS



1. Medicaid wants to collaborate and agrees that kids shouldn't grow up in nursing homes. Help them think about the costs...will it take redirection or new direction (Mark Trail- DCH)
2. Talk with schools in the communities where kids are from (Marlene Bryar- DOE) 
3. Identify the kids, families, and their needs (Beth English – Easter Seals)
4. Try to get the Speaker to appoint the oversight committee.
5. What do we need to do to close the door so kids don't go in? 
6. Need people assigned to help work through the barriers...we know some of them
 - ...custody issues
 - ...federal issues with waiver
7. Make sure that kids and adults with disabilities are involved (Pat and Bernard)
8. Analysis of policy issues that influence placement (Gwen Skinner)
 - For kids in placement have a frank discussion with their families about how it happened that it went in that direction...what broke down...and what needs to be written to prevent those occurrences
9. Support Mrs. Perdue's Foster Parent Initiative
10. What has worked
 - ...what people have figured out
 - ...stories
 - ...lessons learned
 - ...help point out solutions
11. Need to help the front line folks understand
 - ...the vision
 - ...why it is better
 - ...the role they can play
12. What are the possibilities
 - ...information for parents
 - ...parents to help other parents

SMALL GROUP DISCUSSIONS

WHAT MAKES A GOOD HOME FOR A CHILD? There's no place like home !!!!!

Safe place	Where you can be independent
Family that is nurturing, caring, and supportive	Where you can take chances
Stability	Where you can be dependent
Away from constant fear	Have choices
Structure, rules, supervision they can rely on	A sense of pride in you
Comfortable – where you can relax	Respect
Have some control over the environment	Positive Discipline
Combination of dependence and independence	Learn about community & friends
Flexibility	Cultural traditions
Patience – understanding	Acceptance & appreciation of who you are
Fun	Environment rich in learning opportunities
Sanctuary – haven, refuge	Encouragement and Freedom to try new things
Relationships – positive role models	Safety net for when you mess up
Siblings – learning to be in relationships	Respect for privacy
Cultural identity and rituals	Music
Faith	Art on the refrigerator
Love...committed and bonded with parents	Chances to play...toys
Talents and gifts that someone will recognize	Good home cooking
Growth – development is guided	Place where you are always welcome
Basic survival needs are met	Good touches – hugs, love pats, etc.
Food, clothing, shelter, medical care	Own personal possessions
Friends can come over	Your room reflects your interests
Can make mistakes	People who will stand up for you
Challenged	Support when you need it
Comfort foods	Opportunities
Unconditional acceptance	Recognize your individuality
Inclusion / Belonging	Freedom to explore
Builds a sense of identity	You know about the light in the fridge
Parents engaged with the child	Where you can express anger without fear
Sharing is learned	Where you can hang out outside - yard
Where you can voice your thoughts	Help you go on outings (camping, boating)
Safe to leave...you can come back	Welcome real friends to the house
Guidance	Parent / caregiver has faith in you
Learn boundaries	Color / variety / diversity
Safe structure	Has nick knacks and pictures of the family
Where the child is valued	Place to make memories
A place to learn life lessons	Meal times with the family
Transmission of family values, stories, heritage	Some stress – that 's life
Nurtured	Where people will hang in there with you
Where you contribute	Cheerleaders & champions for each other
Feel a part of a family	People who care about the child

WHAT MAKES A GOOD HOME FOR A CHILD?

Comfortable surroundings, access
Involvement in typical family life
Chores, playing, unstructured time
Stable caregivers they can trust
Builds self confidence
Helping kids develop a sense of connectedness to the world
Helps develop values
Faith / Spirituality
Safe place to take risks and discover who they are as individuals
Place where they don't sweat the small stuff
Clear Expectations - Aspirations
Constancy
Encouragement
Where someone really listens to you
Someone who always takes your side
Place where you are held accountable
Where people spend 1:1 time with you
Where you get to express your 2 cents worth
Lots of hugs
Where you are corrected when you do something wrong
Where people believe in you
Surrounded by people who love you
Okay to scream, holler, and "gosh" to express upset
Economic stability
Cleanliness
Where people look you in the eyes
Where people really know you
Where you can be naked
Promotes self esteem
Helps you develop your leadership skills
Motivates you
Provides a moral compass
Learn to "play fair"
Freedom to express your opinions
Free from neglect
Place where the child feels special
Healthy, permeable boundaries
Protection
Loved...no matter what
Your own pictures on the wall
Personal space
Where you have a meaningful role
Unconditional love
Feeling of ownership

Find joy, happiness, and welcome
Help you get where you need to go
A foundation to build a future on
Opportunity to do ordinary things
It smells good
Pets around
Have / know neighbors
Show affection

GOOD HOME FOR A TEEN

Room for personal belongings
Older couples
Experienced Parents
Don't sweat the small stuff
Balance with freedom / authority
Expectations
Access to adults besides parents
Recognition that it isn't always
about disability... may be
about being a teenager



HOW DO YOU KNOW WHEN A LIVING ARRANGEMENT IS NOT A GOOD HOME?

No choices
Failure to progress
Negative changes that indicate abuse / neglect
Constant chaos
Too much stress and no emotional outlets
No hope – no help
Lack of Money and support
No structure nor positive structure
Always being put down or chastised
No positive reinforcement
Lack of options and freedom
Lack of accessibility
Hurried all the time
Individual needs not met
Bug infested
No safety – bad neighborhood with gunshots / crime
Lack of individuality
Sterile environment – smells like alcohol
Constant confinement – imprisoned
Nothing to show who we are – memorabilia/pictures
Mattress on the floor – nothing else
No love
An institution
Too many people
Housebound, little community access
Inconsistent caregivers
Surroundings subject to change
No influence over surroundings – sights, sounds, smells, pets
Every activity is a “therapy”
Not the kid’s pace
Lack of flexibility in rules that allow for development
Who is in charge?
Family visits are scheduled
Low expectations
Focus on disability
Child doesn’t have a strong champion
 who dedicates lots of time and energy
 and celebrates their successes
Not responding to child’s individual talents, interests, hobbies, etc
Everyone engages in group activities
Focus on cost savings
Not having a clear vision for the child
No supervision

WHEN DO YOU KNOW WHEN A LIVING ARRANGEMENT IS NOT A GOOD HOME?

3 Shifts or 2 Twelves

Pressure to conform

Segregated from the real community

No knocking on the door – keys jangling

No one calls to talk to you

Where you are a number, patient, client, consumer, individual

Where you are not called by name, but rather by label

Where people talk about you but not with you

When volunteers come to play bingo with you, crafts, gospel singing

Where you don't see kids from real school

When you can't eat when and what you want

All you can do is stay in bed

No therapy

No baths

Get 30 minutes of education a week

No braces or braces are not put on

Throw up because you can't use the bathroom

No water

No attention to medical symptoms

Bad environment

Parents are rarely there

Destruction

Not clean

When child is fearful

No privacy

Too regimented / rigid

Does not provide the basics

Financial instability

No love

Bad associations / adults or children

When child seeks love/attention outside the home inappropriately

Decisions made by others

Lose sense of identity

Paid, transient, not permanent caregivers

No control of environment

Scheduled

Individuals that are not inter-related

Van out front with a sign on it

Special zoning required

Fire codes / drills

Lack of personal value (except \$)

Fluorescent lights on all the time in the halls

Hard surfaces

HOW DO WE KNOW WHEN A LIVING ARRANGEMENT IS NOT A GOOD HOME?

Locked doors without a key
Behind a fence
Friends cannot visit at will and have to sign in
Have an assigned case manager
Physical needs are not met
Emotional needs are not met
Too many structured activities
Too isolated from either family or other kids
Can't depend on caregivers –inconsistent care
No significant other
Lack of recreational things...toys, etc
Lacks color
Can't have your own possessions
Not accepted as a unique person
Labeled – categorized
Favoritism
Lack of relationships
No voice – people make decisions for you
No support for becoming independent
No choice of roommates, housemates
People are “assigned” to you
Where you exist but do not belong
It is a business and you are kept there
When you are ashamed of where you live
When you have to sign in and out
When there are visiting hours
No choices in when to eat or what to do
People are paid to be with you
When there is not enough support
Fire Exit signs
No personal things
Write your name on everything
You can be moved at anytime
Threat of being moved out because of your behavior
Money drives your care
Doesn't reflect individual's personality
No place to bring friends
Limited opportunity for education
Don't get to go outside
Isolation
Disconnectedness
Set menus...don't get seconds
Loss of your history / personal story

HOW DO YOU KNOW WHEN A LIVING ARRANGEMENT IS NOT A GOOD HOME?

No little life pleasures – naps on the sofa, good food, snacks in the fridge
No flexibility on when you go to bed or when you get up
Sleep in a room with lots of people
Living with strangers / anyone might move in or leave abruptly
No one remembers your birthday
Large building with many toilets, tables, etc
One size fits all rules
No long conversations over meals
Rules, barricades for all even though only one person needs it
No one is looking out for you
When people are unhappy most of the time
Have to wait your turn to get out of bed, bathe, eat, etc

WHAT IS THE IMPACT OF A BAD HOME ON THE CHILDREN?

Low self esteem
Lacks social skills
No lasting relationships
Life wasted
Fear
Isolation
Lonely
Abandoned
Rejected
Poor mental and physical health
Instability
No attachments
Emotionless – don't cry when most kids do
Confusion – Who am I...Where am I from
Quiet, shy
Kids who hurt self and others because they hurt
No sense of past
Rigidity / routine...mealtimes, bed times
The abruptness of becoming an adult at age 18 if DFCS involvement
No sense of purpose, trust, relationships
Limited connections to society
Lack role models
Increased cost to the system
Surviving vs Thriving
Limited development
No sense of having a future
Failure to grow, stretch, and learn

IMPACT ON THE KIDS?

Can't develop a sense of self
Labels define rather than personhood
Increased dependence – physically, mentally, emotionally
Depression
Over medication
Acting out
Become clients for life
Stereotyped / Stigmatized
Learn a different language...spoken & unspoken language of the institution
Kids get in trouble to get attention
Run away
School failure
Substance abuse
Missed learning opportunities
Child abuse
Lack of trust
Removal from home / feeling of instability
Aggression / bullying
Sexual acting out
Lack of friends
Loneliness
Don't learn what it is to be in a family
Poor boundaries
Lack self confidence
No development of identity – culture, religion, talents, skills
Physical harm
Seek attention in the wrong way for the wrong reasons
Not enough love
Develop inappropriate behavior
Slows or halts development
Become known as your label
Fragmented
Lose relationship with siblings
Limited visits with family
Makes it hard to reconnect
Lower expectations
Sometimes treated like a child forever
Lack of respect
Personal possessions are at risk of being taken
Hard to make your own decisions
Impacts parents / siblings, too...family isn't whole...feel the loss / broken
Sense that they did something wrong
Diminished as a human
Emotionally damaged

IMPACT ON KIDS?

Dreams are dashed
 No goals nor expectations
 Socially disaffected

WHAT DOES HOME FEEL LIKE FOR EMMA AND DONALD?

EMMA	DONALD
<p>Snuggles in recliner Has a dog Is loved Has security & stability Competent care Fantastic wardrobe More community interaction Lots of activities Schedule that is tailored to her and she can count on it Gets to eat real food “apricots” Accepted Happy Safe Pretty Gets kisses and hugs All needs are met World is her oyster Tucked in Read a story With her 1:1 Gets what she needs Has her mom 24/7 Part of a family Nurtured Warm Safe Goes to school Progressing Permanent Healthier – fewer seizures Lots of ways to feel special Out & about at will Cuddly, warm loving relationship Relaxed</p>	<p>“not dressed up...no where to go” Very little stimulation Low expectations No opportunities Not safe Poor & inconsistent care Lots of different people providing care Not valued Misses family Viewed as a baby Loses chance to be with other kids Isolated Scared Feels unimportant Hopelessness Lost Doesn't know “home” Confused Unstable / insecure Abandoned No choices Loves when family visits On a schedule set externally Has stuffed animals Has a TV/VCR from mom Spends time in a Geri chair Limited outdoors / out of room Medicaid determines out of facility time Medical intervention every day Eats gross food Always waiting Regressing People do things to Donald Victim of neglect Family tries to make his room “home like”</p>



WHAT DOES HOME FEEL LIKE FOR EMMA AND DONALD?

EMMA	DONALD
<p>Celebratory Full, well rounded life Variety of activities Important relationship with significant other Clean Real / ordinary life Good health care Age appropriate</p>	<p>Lots of time in bed Boring / un-stimulating Limited No friends No choices Painful No fun Kept inside No social activities Regulated Confined Deprived Rigid – cold Dangerous Sad Lethargic Hopeless No dignity Like living with house full of grumpy people 3 shifts a day/ 3 hots & a cot</p>

WHAT WOULD IT TAKE TO GET DONALD OUT OF THE NURSING HOME?

<p>Custody resolved Ramps built Wheelchair that fits Respite Day time care Once a month nurse Liberty school Home with support School with support Friends Memberships as he gets older Ask the family what they want and need Adult support network for mom Somebody to look at the big picture and the details Needs a physician / pediatrician Medical equipment</p>	<p>Training on using the feeding tube In-home support Therapy services Transportation Home modifications Money to pay for the things needed Stable funding source - Waiver Accurate assessment of child's need Reliable medical support Commitment to make it happen Training A "go to" person Professional to monitor health care Peer Support Leadership Welcoming community</p>
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WHAT WOULD IT TAKE TO GET DONALD OUT OF THE NURSING HOME?

Accessible van
Modified bathroom
Personal support waiver services
Ally to help navigate the school and service system
SSI
IEP
Recreation opportunities
Adaptive equipment
Church family
People...and more people who care about and for Donald
Medical supplies
Nutrition
Routine and emergency medical services
Commitment/ Determination / Will to help his family bring him home
Advocacy for Donald and the family
Legal support
Link to community resources (Children's Medical Services)
Someone to ask Mom...."What do you need?"

WHAT ARE ALTERNATIVES TO CONGREGATE SETTINGS?

Foster care with a family
Home with family....may need to do it in small steps
Adoption
Group home with young people
Living with other relatives (aunt, uncle, cousins, grandparents, siblings)
Step down care
Family support for families in crisis
HOME...There is no place like home
Kinship care
Therapeutic foster care
Having their own home with support and chosen housemate
Not group homes
Host homes
Shared parenting
Family support for all families
Apartment with preferred roommate
Apartment by self with outside support
Intentional community...shared responsibility...shared joy
Co-Op
Transition Home for kids who are medically fragile
Someone to hold parents hand all the way down the road
Access to GAPP or SOURCE programs

WHAT ARE THE BARRIERS TO FINDING HOMES?

Complete lack of information about what's available for families
The system and its Rules
Families made to feel they are "users" if they need supports, feel guilty
asking for help even when it's desperately needed, feel like they need
to constantly justify need
System designed for acute care, not longterm support
Families are busy and tired
Families sick of having to chase help and then (to add insult to injury) get labeled for it
Get off your butt and do it
Can't believe it can be done
Fear of the unknown
Deficiency based instead of strength based system (DFCS & medical system)
HIPPA
Lack of nursing services in rural areas
Making modifications to home
Education of families of kids without disabilities
Education of the school systems
Sabotage by medical staff
Nurse Practice Act needs to be changed
It's somebody else's job
Lack of committed recruiters in communities
Custody issues
Finding families
Money to support
Medical assistance
Deal with regulatory issues
Lack of back-up services
Back filling the institution
Lack of transportation
Employees Union
Organized parents against de-institutionalization
Economic impact argument
Insiders attitude - Old school – not forward thinkers – maintain status quo
Need to use money differently
Don't have full force recruitment of foster families
Need to expand and design/redesign community services
Current system is developing group homes
Lack of commitment to it
Not anyone's job – No accountability
Bureaucracy – Red tape
Labels – How we describe people
We set up barriers so it is hard for anyone to get to know a child
Families share stigma – "Incapable of Care"
Community fears

BARRIERS

Takes time to bring people and the community along
Will the family be able to get the medical supports the child needs
Finding and matching child with the right family
Support services (case management, therapies, respite)
Current agency policy and procedures
Lack of high quality help
Assumptions and pre-conceived notions
Lack of support to biological families (all or nothing)
Lack of opportunities to build relationships
Lack of technical support
Liability issue
History...the way it has always been
Need to learn how to listen and talk with parents
Provider system in the community
Need to remove the institutions as an option
Strong nursing home lobby
Need chances to get to know the kids
Overcoming confidentiality issues
Finding the families
Good planning and making sure the pieces are in place and implemented
Need a choice and range of services in the person's community
Need flexible funding and creative financing
Families need more control
Lack of responsiveness and accountability
Need community development with faith community and social groups
Need people who accept you and your child without having the whole story
Lack of shared parenting
We don't embrace it's importance
Children are invisible and anonymous
Getting started
Thinking that you have to have all the rules first
Myths about foster parents and adoptive parents
Child custody – helping people who can't provide the care “let go”
Attitudes – “stinking thinking”
 Child with disabilities is a burden
 People with disabilities should be in institutions
Fear of communities and families immobilizes them
Inadequate legislation
No resources
Lack of communication
Stagnant – no plan for movement
No vision / passion / inspiration
Mindset
Lack of access to specialized health care
Lack of safety nets
Lack of medical equipment...things that Medicaid doesn't pay for

WHAT ARE STRATEGIES FOR OVERCOMING THE BARRIERS?

Forums to give people in the community information and bringing families with kids with disabilities to introduce them to their “neighbors”

Collaborating with other “non disability” focused organizations

Sharing the goals of this summit with interfaith disability network

Introducing children and families to local parks and recreation department
Playground, after school / summer activities

Also Kiwanis type organizations for specific requests

Multi-tier approach family to family, community, broader public (long term)
Change attitudes

Tell stories (who are the children? Put a face to each child)

Clear sense of direction

Change organizational structure – involve families from the start

Be creative

Look at successful states and programs

Targeted recruitment

Train

To realities of children who need the homes

Slow, careful, deliberate training in family

Have support in place

Look for missing family members. Sometimes we don't know there is family

Education of families, churches, civic groups, just plain folks, city / county people,
and legislators

Recruit community person with credibility – make it a non-system person

Develop a pool of nurses....volunteers, paid

STRATEGIES FOR OVERCOMING BARRIERS

Let children know that other kids live in institutions who belong in their town...ask their help

Stories of each child with their gifts...make it strength based
Make each story personal as if this were my child

One child at a time

Schools – kids learn about how we are more alike than different – diversity

Continue working to change the nurse practice act

Talk to our own medical professional to educate

Project DOCC – expand statewide

Peer support just for kids – girls club/boys club, etc

Pair family up with another who is scared to bring their child home

Keep vision alive...No child in GA will go to an institution...Kids need families and belong in families

Ensure support system is available

Services fit the child's needs

Existing “mo” money....restructuring

Talk and listen to families...address their fears

Develop ambassadors to the community for each child

Work personally – one person at a time

Do it right – we know how

Avoid group home models....that leads to rejection

Create some new job descriptions so current staff might take someone home to their family

Tell stories....take time to get to know each child....be careful of the language used

STRATEGIES FOR OVERCOMING BARRIERS

Have adults and children with disabilities help

Have families who have helped their family member move out...talk to other families

Need a reliable, responsive service system....Help providers think about reinventing supports

Make a formal proclamation that institutions aren't good places for people.

Georgia should consider cash subsidies to families

Make it people's jobs to do the asking / recruiting.

Set up study tours so people see what is possible

Make sure the money saved by closing institutions goes back into community services

Media message – select speakers – every group BLITZ

Do whatever is needed – commitment

Elevate direct support professionals to a living wage

Realize the importance of the partnership with local school systems

Flexible funding and \$ follows the child

Pool resources from supporting agencies (DHR, DOE, VR, HUD)

Educate community through stories in various media and being present

Share what works.

Really expand training for MDs

Find kids' hidden talents

Keep parents informed...supported and connected with each other “date night”

Develop legal expertise in helping work through custody issues

Make programs offer supports more flexible so they can be accessed when people need them

STRATEGIES FOR OVERCOMING BARRIERS

A neighborhood organizing approach e.g. “granny house” idea...mutuality of support

Solving problems with people rather than running programs

Making problems manageable rather than allowing problems to stay BIG

Make sure we plan for supports for teens....not all of the 142 are little kids

Big scale service delivery models may not be the best approach...Look at small, personal, community based vs. mega companies

Issue: \$ redefine has to happen, timing wise, so that a whole unit can close /\$ can get reallocated

Find out how kids got in these places. Learn from this and create new policies / practices to keep it from happening

Facilitate introduction to community opportunity / associations based on strengths, talents, skills, and interests of the children

Help people have valued roles – being servers, not just being “served”

Ask, Ask, Ask

Schools finding roles / places to include kids with disabilities

Working from the inside out

Restructure people’s thinking

Make sure people have open access to spend time with the kids

Learn more about SHARED PARENTING idea

Impress on the hearts of the leadership

Look to people who have experienced discrimination for leadership in overcoming discrimination in this area

Teach inclusion to teachers

Identify families that have been successful – ask them

Pull institutional resources toward the community

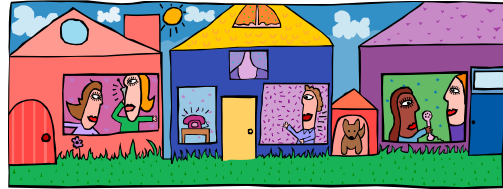
Use Adults with disabilities as peer support specialists...People 1st

STRATEGIES FOR OVERCOMING BARRIERS

Development of a “medical home for medically fragile kids”

As for family support from families who have already experienced transition to community

Start a ground swell by getting started



HOW DO WE ENGAGE COMMUNITIES?

Tell your personal story to the media...and have a broad message, too

Visibility of families (education by being present)

Be present / visible in your faith community

Educate....know what you need....be specific....share the gift...have a clear vision

Ask for help....Adopt a family / a child

Communicate...communicate

Welcome and value differences and likenesses of kids

Explain and show what children can do

Expose community to people with disabilities

Hold block party....barbecue

Neighbor to Neighbor...one at a time

Introduce people

Pair a child with a church....may provide respite or other support

Patty Peaks...connector / opinion leaders

Just ask...find a reason...what is in it for them

DD, Medicaid, and DFCS work together to develop response to this issue

HOW DO WE ENGAGE COMMUNITY?

Infiltrate the leaders of the community at their level

- a. identify
- b. join organization
- c. develop media presentation
- d. speakers bureau (home folk to deliver message)
speak to every organization in community
- e. Develop and use relationships and friends to expand ideas and show how it can be done

Demonstration – one success at the time...tell the story and replicate

Include all players and community in solution circles

- a. develop services locally
- b. identify barriers and form solution circles

Never give up

Have celebration of successes

Share historic perspective / institutionsthen tell the stories

Stories / history may be ways to connect people

Need more people telling the stories

Need to tap the wisdom of grandmas and grandpas

Create kitchen table conversations...make it snowball

Have a clear message

Remove anonymity

People have to see the child

Need to engage other children...we are missing the voice of other children

What would you want if it were your child?

Recruit allies

Keep it as a family approach...this decreases the resistance

Help build positive reputations for kids

HOW DO WE ENGAGE COMMUNITY?

Link with faith based groups...get to know the church secretary
Create a culture of giving gifts and supporting each other for everyone in the congregation

Know the community movers and shakers

Need advance assurance that the supports will be there

Help people learn how to ask

Involve high school and college kids....they need community service on their resumes

Help prepare kids for transition....relationship building

Community people aren't as connected to associations now...brainstorm how to reach individuals in the community

Build circles of support for each child....keep ties...search out other relatives

Asking needs to be done by a LOCAL person...(county by county)

Create symbols – like the bracelets connecting kids on “inside” with kids on the “outside”

Talk with and engage individuals at parks and recreation and after school programs

Clubs and organizations (moose, elks, American Legion) presentations on inclusion

Finding connections...building connections through combined activities
Building accessible play grounds together

Education

- Neighborhood pot lucks
- Making community accessible
- Keep it simple

Vivian Paley... You Can't Say You Can't Play

Modeling for children “everyone gets to play”

Get rid of assumptions

Each of us taking personal responsibility for a child...finding homes and supports

Get rid of language that continues stigma....use person first language

Have community resource fair to educate and meet children with disabilities

Keep educating schools

Help parents be advocates

Re-engage parents

Parents supporting parents

Say it is okay to ask questions

Raise awareness through public service announcements

Stay persistent...don't assume it is important to everyone

Brainstorm how to keep it "charged up"

Take responsibility for confronting segregation when it occurs

Teach respect for all life stages (personal space, respectful language, etc)

Age appropriateness

Values....top down, bottom up, throughout the middle

Raise awareness at zoning boards, business licenses bureaus, other govt. employees

Bribe neighbors with brownies

Make people stop speaking in code and force bias into the open

DO WHATEVER IT TAKES !

Notes / Comments: