



***The Challenge of Working with
Different Partners***

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SUBTITLE:
**Delivering on the hope and promise
(s) of the UN Convention**
Community Living
with
Supports and Services
for All.



This conference is about:

- The right of disabled people to make decisions for themselves.
- The right to be included in the community.
- The right to inclusive education.
- The right of families to get the support they need.
- The right to live without poverty and discrimination.

I am an American



- I talk fast.
- This is my social disability.
- Please let me know when I am speaking too fast.



Today I want to talk about:

- Many different organizations working together to make the promises of the convention come true everywhere
- Some ideas about working together
- One fable and one story from the United States

What is Collaboration? Why Collaborate?

- Collaboration is when people and organizations come together to accomplish a common goal.
- Good collaboration leads to:
 - better programs
 - better public image and
 - better use of resources such as \$ or € or £.
 - better use of staff resources.



Like anything else there can be problems...

- Organizations protecting their “turf”
- Mistrust
- Not working together during a crisis
- Slow decision-making
- Loosing your “voice”

Some strategies for effective collaboration:

- **Define The Real Issues**
 - Involve the right people
- Gather necessary information
- Symptoms vs. root cause
- Keep asking “Why?” and “How?” and “Then What?”
- Fix the problem, not the blame



**Collaboration is not a topic limited to
deinstitutionalization or the UN
Convention**

Important to know what the
literature says on this topic.

The Little Red Hen

Sara Cone Bryant
(Retold from Joseph Jacobs)

**One day as the Little Red Hen was
scratching in a field, she found a grain of
wheat.**

"This wheat should be planted," she said.

"Who will plant this grain of wheat?"

"Not I," said the Duck.

"Not I," said the Cat.

"Not I," said the Dog.

"Then I will," said the Little Red Hen.

And she did.





**Soon the wheat grew to be tall and yellow.
"The wheat is ripe," said the Little Red Hen.
"Who will cut the wheat?"
"Not I," said the Duck.
"Not I," said the Cat.
"Not I," said the Dog.
"Then I will," said the Little Red Hen.
And she did.**



**When the wheat was cut, the Little Red Hen said, "Who will thresh the wheat?"
"Not I," said the Duck.
"Not I," said the Cat.
"Not I," said the Dog.
"Then I will," said the Little Red Hen.
And she did.**





When the wheat was threshed, the Little Red Hen said, "Who will take this wheat to the mill?"

"Not I," said the Duck.

"Not I," said the Cat.

"Not I," said the Dog.

"Then I will," said the Little Red Hen.

And she did.

She took the wheat to the mill and had it ground into flour.

Then she said, "Who will make this flour into bread?"

"Not I," said the Duck.

"Not I," said the Cat.

"Not I," said the Dog.

"Then I will," said the Little Red Hen.

And she did.





**She made and baked the bread.
Then she said, "Who will eat this bread?"
"Oh! I will," said the Duck.
"And I will," said the Cat.
"And I will," said the Dog.
"No, No!" said the Little Red Hen.
"I will do that."
And she did.**



From The Gingerbread Guide: Using Folktales with Young Children. Copyright 1987 Scott, Foresman and Company.

The moral of the story is....

- Individual disability organizations have succeeded in the past by doing the hard work themselves.
- In part it is why they have been successful.
- But what worked in the past may not work in the future.....

– Another story



A Better example of Collaboration



- The organizations that began planning in 2003 wanted to get broad buy-in to statements and ideas on full community inclusion.
- Some of them had worked together on another big effort in 2001, others had not.
- The U. S. Self-Advocacy organization, SABE, came in after heated discussions and a series of demands.
- By the time the 2005 Summit was held, 10 national organizations were involved, and more than 2,000 people came to Washington, DC.
- One goal was to put to rest, forever, any argument in favor of institutions.

Working with Partners can accomplish major goals.



AFP is united in its commitment to the successful inclusion of people with developmental disabilities into the mainstream of American life. By bringing together the many voices in our organizations dedicated to this cause, we will work together to make this vision a reality.



- The first time the Alliance had a national gathering, in 2005, there were 10 national organizations involved.
 - The goal was a full community participation for all people...
 - no institutions
 - no workshops
 - no segregated schools.
- The 2011 gathering has 15 organizations, with one goal....
 - By 2015
DOUBLING THE
NUMBER OF
PEOPLE WITH
INTELLECTUAL
DISABILITY WHO
HAVE REAL JOBS
IN THE
COMMUNITY.



The success of the first Alliance for Full Participation summit led to more organizations wanting to join in.

*** ALL OF THE ORGANIZATIONS
ARE DISABLED PEOPLE'S
ORGANIZATIONS AND THOSE
RELATED.**

***WHAT ABOUT THOSE
ORGANIZATIONS THAT SUPPORT
EVERYONE IN A COMMUNITY?**



Silos are good for storing corn



They are not so good
for people with disabilities.

But, seriously, there are two
issues with Silos...



Silo Type 1

- Silos that represent the different areas of community life.
- They are readily crossed by people without disabilities
- Some people with disabilities need support.

Silo Type 2

- Silos that are disability specific programs, by category, with varying eligibility and services.



What do you want from the silos?

- Is the goal to make the silos bigger?
- Is the goal to make it easier to move from silo to silo?
- Or is the goal to find something better than silos?

Why Silos? *continued*

- Silos allow a focus for identification, legislative advocacy, rules and regulations.
- They can be identified for discussions and debates about common issues.
- The question is...**have they outlived their usefulness?**



Why Silos?

Silos were built for specific purposes by families, professionals and self-advocates and, in many ways are functional.

To fulfill the promise of the U.N. Convention, I think we need something better than silos.

- Can we count on our governments to come up with things better than silos?
 - Legislature, Executive Branch?
 - They still run the institutions and show no signs of getting out of that business.
 - It took decades of litigation in the US to get government to do the right thing.
- Services for people compete with many other priorities.
- The economy is bad in many countries.

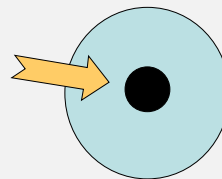


Reminders

- A waiting list is not a support or a service.
- Good quality services do not necessarily equal a good quality of life.

What To Do???

We can't stay
on this spot



We need to rethink what
we do – affirm our
values but resolutely
search for “value”



The next stage in collaboration, to make the promises of the U.N. Convention come true, requires collaboration with organizations that are not disability organizations.

- This is harder.
 - They may not always share our values about people with disabilities.
 - But we need organizations that do:
 - Housing
 - Business and jobs
 - Health Care
 - Education and Training
 - Transportation

Some things requiring collaboration in the future

- Conversion of programs that are facility based to those that include people in the life of the community – not just institutions
- NGOs - growth due to innovation
- NGOs – In some countries, merger/or partnership collaboration to build infrastructure
 - Combine strenghts



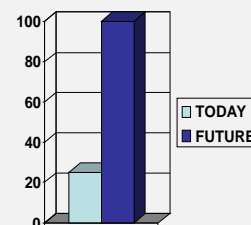
Important Principles in Collaboration

- You cannot compromise on your core values and principles
 - Realize that sometimes you must compromise on some things
- Try to find ways where everyone wins
- Communication must be clear and often
- Find ways, and agree in advance on rules, to solve disagreements
- Share credit for successes

There is huge gap between what is best practice and common practice.

If all supports and services available today were as good as the best that are available

- The quality of life for people with intellectual disability would improve worldwide more than all the progress in the past 50 years.
- **We all share the responsibility to fix this.**
- **That is why Inclusion International exists.**





The Challenge Lies in Changing What We, Not Others, Have Developed

- It was easier when we could blame the “bad” institutions.
- Much of what is wrong in some countries now is what “we” created.
- As we wanted to do good things for people, how could this be?

The Challenge Lies in Changing What We, Not Others, Have Developed

- Providers of services are doing what we asked them to do in the past.
- We are now telling them they must change-to do something different!
- Debate and discussion are good, but not changing is **not** acceptable.
 - The UN Convention is about the rights of persons with disabilities, not the rights of service providers.



People Who Earn Their Livelihoods in Systems Will See Major Changes

- They must be nurtured and supported as we move forward
- They are not the enemy
- Providers are not the enemy
- The state is not the enemy
- ***Complacency is the enemy***

For NGOs Providing Services... Working with Advocacy Organizations

- In many places, this is happening daily.
- Recognize the tension between maintaining existing services-cost of living increases-and serving people who are waiting.
- Tension between what we know how to do and what we should know how to do.
- Need strategy for dealing with the growing inequity in the field.
- We are known by the company we keep-stop defending the indefensible.



Long Term Supports is Not A Place

- The movement to deinstitutionalization people has mostly been about real estate.
- The promise of the Convention is to improve how people live and to help people get their rights.

The Convention Promises families and people with disabilities so much

- Inclusion
- Self-Determination
- Services and supports when needed
- Acceptance in their community
- Chance at the good life possible in the community
- A job, a decent place to live, friends



Yet...

- Are we prepared to deliver?
- Do we have the courage of our convictions?
- Do we have what it takes?
- Can it be done?
- Can it be done where you live?

We have promised so much... and we **cannot** fail to deliver on those promises.

But have we over promised?



Most Importantly. . .

- *Listen* to people with disabilities -- as participants, as advisors, as consultants, as friends, as colleagues
- Don't be afraid to confront the complexity and see a way through it
- Don't get hung up in orthodoxy -- what matters is the outcome
- Don't take it personally!

It can be done.

- Only you can do it.
- It will be hard work.
- Figure out the what first, then the how, then the strategy to sell it to government and interest groups.

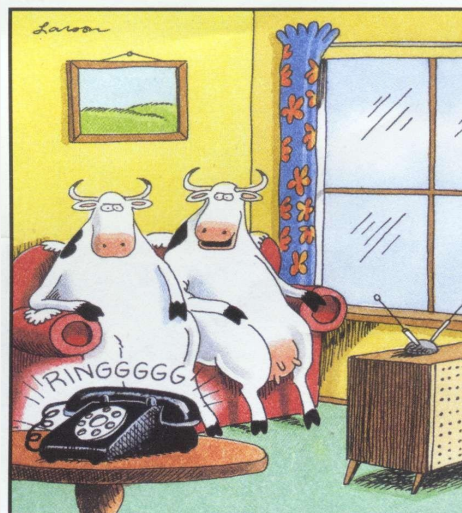


Justin Dart, an American disability advocate always said... "get involved in politics as if your life depended on it...because it does!"

So given all our constraints, what now?

The trouble with our times is that the future is not what it used to be.

Ambrose Paul
Toussaint Jules
Valery 1871-1945



"Well, there it goes again. ... And we just sit here without opposable thumbs."

The future ain't what it used to be.

Yogi Berra



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