



**“Uniting for a Healthy Future:
Integrating Systems for North
Dakota’s
Children, Youth, and Young Adults”
2nd Stakeholder’s Symposium**

WELCOME

Dr. Brent Askvig

Dr. Rich Roberts
Champions for Inclusive
Communities

Session I

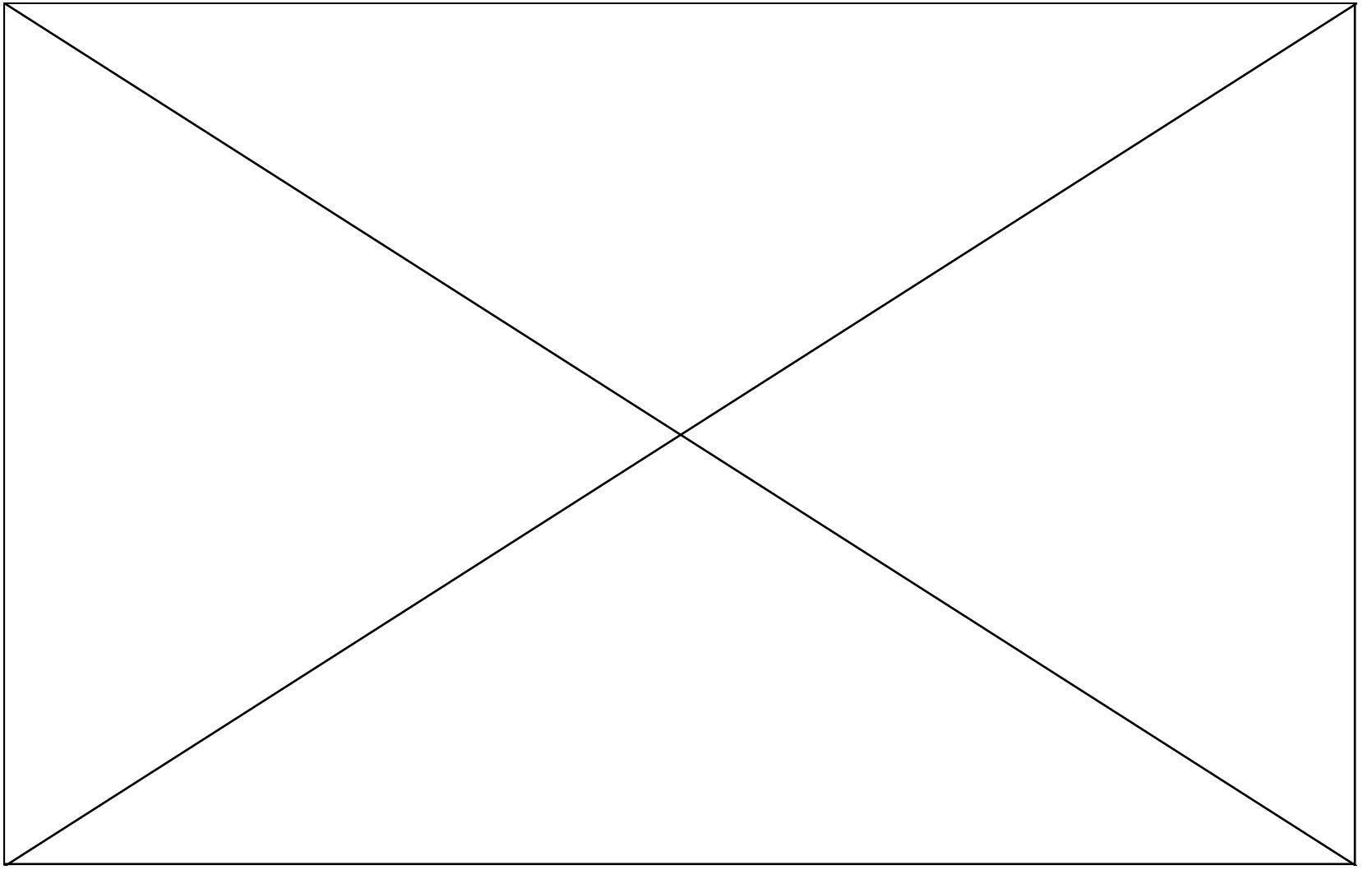
<http://www.youtube.com/watch?v=VwoRMAC461A&feature=related>



**Champions for
Inclusive Communities**

Systems Building for Children with Special Health Care Needs and Their Families

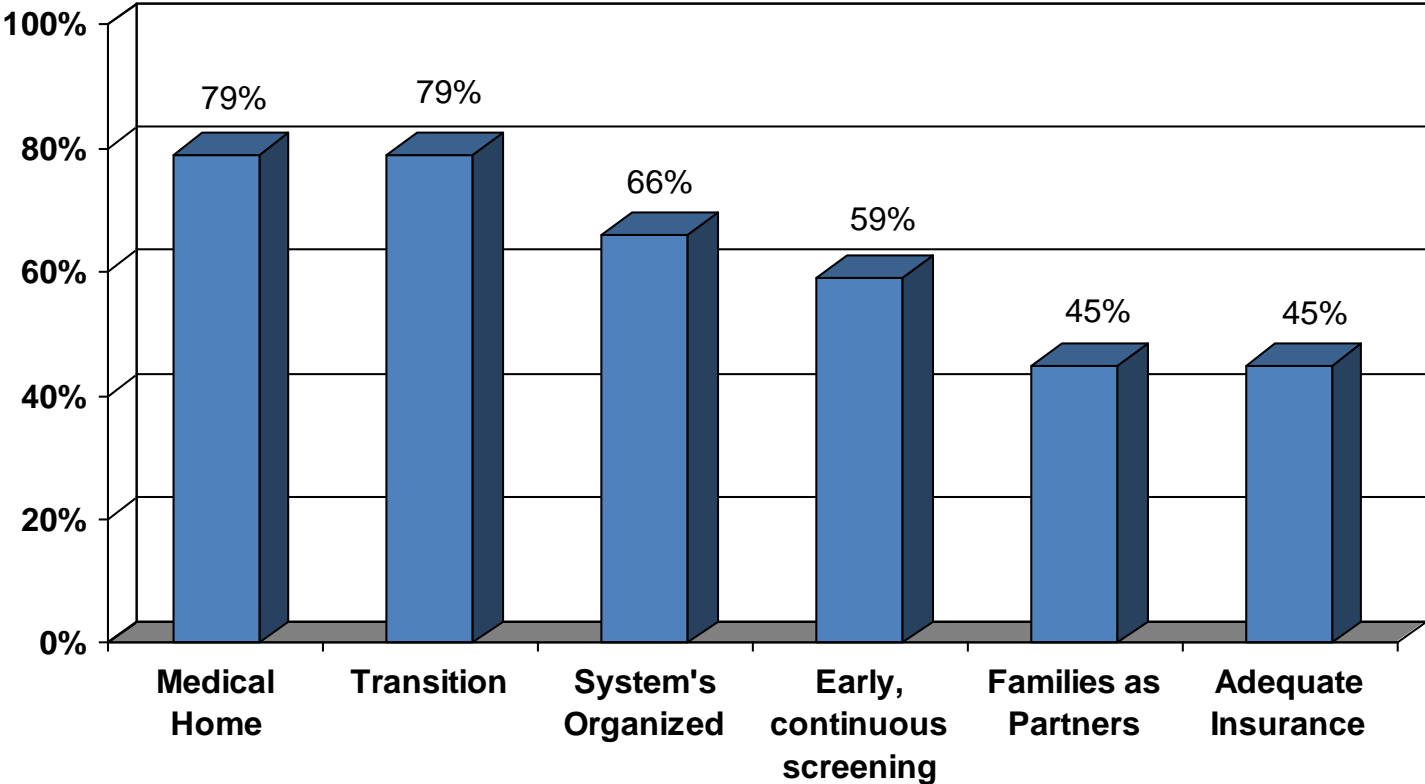
Richard N. Roberts
Utah State University



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Which of the 6 CSHCN goals are most immediate priorities for states?



Characteristics of Strong Leaders

-
- Leadership that emphasizes exchange of ideas, voices
 - Collective leadership based on democratic principles
 - Tasks are directly linked to accomplished goals
 - Use incentives to reward/motivate

Implementing Community-Based Systems of Care

- Ensuring families are supported as decision makers
- ★ Optimizing community-level responses to meet transition needs
- ★ Developing a system to support care coordination

Champions' State Needs Assessment

1. Assessed priorities regarding:
 - building partnerships
 - implementing community-based systems of care
 - measuring progress
 - six CSHCN performance goals
 - receiving information/support
2. Used to guide Champions' activities

Key Ingredients for Developing Plans

A concrete, clear mission combined with quality plans and attainable goals is essential.

- **Keep focus on the coalition's priorities and reasons for coming together**
- **Develop short-term goals with high chance of success**
- **Include a range of sectors from the community when appropriate (government, faith based, private providers, business)**
- **Use open, frequent, predictable communication methods**
- **Establish fair problem-solving and conflict resolution procedures**
- **Plan actions that build on the strengths within the community**
- **Develop actions for change that fit within the community's culture**

What is a Coalition?

AKA:

- Collaborative partnership
- Community forum
- Task force
- Consortium
- Coordinating council

A mutually beneficial relationship between individuals, governmental agencies, private and/or public sector organizations based on achieving common goals.

What is the Evidence that Coalitions are Effective?

Synthesized 8 published literature reviews (1996-2006) reflecting 18-80 studies each.

- All were community-based coalitions
- All had a health focus
- Target populations varied

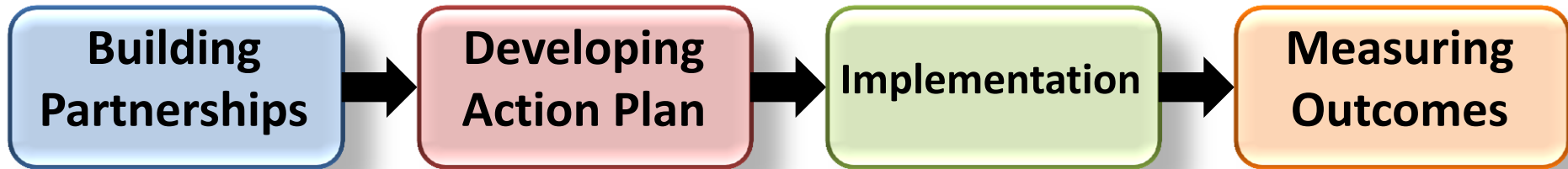
Outcomes Achieved by Coalitions:

- Reduced risky behaviors
- Improved access to services
- Reduced lead poisoning among children
- Reduced infant mortality rate
- Reduced adolescent pregnancy rate

Characteristics of Strong Leaders

- Use incentives to reward/motivate
- Tasks are directly linked to accomplished goals
- Shared leadership that emphasizes exchange of ideas, voices
- Collective leadership based on democratic principles

Consumer Involvement in Coalitions



- **Consumers serve as key decision makers**
 - ✓ Voting member
 - ✓ Co-chair
- **Recruit multiple and diverse consumer representatives**
- **Consumers receive financial compensation**
- **Recruit private providers/business sector**

- **Keep focus on needs of consumers in vision and mission**
- **Design consumer-friendly needs assessment to drive plan**
- **Use frequent, transparent communication methods among coalition members**

- **Consumers obtain access training in leadership, public speaking**
- **Consumers “market” coalition with community members**
- **Consumers get word out to community and change attitudes/beliefs**

- **Develop meaningful indicators of change**
- **Pilot measures with consumers**
- **Consumers help interpret results**

Examples of Community-Based Implementation

- **Enhancing focus on coordination/assurance**
- **Creating interagency application systems**
- **Recruiting and training community-level family advocates**

Building Partnerships

- ★ **Obtaining buy-in from partners through statewide coalitions**
 - **Building effective partnerships with families at systems level**
 - **Building interagency collaboration at community level**

- ★ **Building funding systems, including partnerships with insurance plans and other payers**

Examples of Partnerships

- **Creating task forces on six CSHCN performance measures**
- **Creating buy-in at the community level via “issue briefs”**
- **Establishing youth advisory councils**
- **Developing coalitions with specific assignments**

Key Ingredients for Building Partnerships

- **Mutual respect, understanding, and trust among members**
- **Members represent all levels of position power in decision-making, service provision, and service “customers”**
- **Clearly-established roles for coalition members and coalition staff to prevent confusion/conflict**
- **Clear rules about how to handle conflict/differences**
- **Build skills, knowledge, and positive attitudes of members**
- **Select partners with links to resources and who represent broad sectors**
- **Diverse membership re: ethnicity, age, SES, and citizens**
- **Benefits of involvement are clear and outweigh the costs to members**

How do Title V CSHCN Programs Partner with Consumers?

- **National and State Level Family Voices**
- **State Family to Family Health Information Centers**
- **Family and Youth serve on state councils/advisory boards**
- **Family satisfaction is key outcome**
- **Families and youth partner with the medical home**
- **Support financing for health care**
 - **Family Opportunity Act**
 - **Katie Beckett Waiver**

Key Ingredients for Implementation

- **First step is often changing community *attitudes***
- **Access training opportunities, technical assistance, and support for the coalition**
- **Allocated/paid staff, materials, work space to support the work of the coalition**
- **Secure financial resources for program activities, staff pay, and future needs**
- **Skilled leadership to deal with conflict management**
- **Plan for set backs and be flexible about changing specific implementation plans**

Key Ingredients for Measuring and Monitoring

- **Work with community to identify meaningful indicators of change;**
- **Establish measurement plan that is based on these recommended indicators;**
- **Hold members accountable for creating change –Even if they do not change the policies themselves, they are responsible for getting the public opinion behind them to convince legislators or agency heads to change the policies. Even if they are not teenagers, if their campaign reduces teenage pregnancies, they can feel responsible and celebrate that.**
- **Celebrate coalition accomplishments – frequently.**
- **Keep records of the work accomplished, ranging from meeting attendance and minutes to documentation of policy changes;**

Measuring Progress

- **Appropriate use of state-level data from national surveys**
- ★ **Identifying existing data sources and developing complementary tools**
- **Incorporating CSHCN performance measures into CQI process**
- ★ **Models for interagency data sharing**
 - **Using repeated measures to monitor systems improvement**
 - **Techniques for evaluating community-based contracted services**

Examples of Measurement and Monitoring

- State-level telephone household surveys
- Expanded use/sharing of CAHPS, BRFSS, etc.
- Interagency surveys
- Data warehousing
- Data integration
- Enhanced CSHCN client databases

For More Information About Consumers in Leadership Roles:

www.ChampionsInC.org

www.hrtw.org

www.familyvoices.org

www.medicalhomeinfo.org

<http://ctb.ku.edu>

NDIS Overview

- Activities and Accomplishments
- Medical Home
- Healthy Transition
- Family Involvement
- Cultural Competency
- Partnerships

Session II

BREAK TIME

Uniting for a Healthy Future

What is Working?

What Could be Better?

Session III

LUNCH

On your own

Buffet available in Restaurant

Starting back promptly at 1:00 pm

Planning for a Healthy Future

Your Agency Mission

Session IV

BREAK

MAKING IT HAPPEN

Session V

Q & A

Session VI

Housekeeping

Closing