

Building Pathways to Empowerment

BLUEPRINT FOR CHANGE

In February, 2010 The Arc of Indiana embarked on a campaign, *Building Pathways to Empowerment*, to take a fresh and sometimes hard look at Indiana's system of programs and services for people with intellectual and developmental disabilities.

The campaign began with the formation of the **Big Minds Group**—20 national leaders in the field of developmental disabilities who came together to generate new ideas and lead us in a new direction. Their ideas and recommendations led to five key principles

to guide system reform and change:

- **Building Career Pathways for All**
- **Discovering and Realizing Individual Gifts**
- **Supporting Resourcefulness of Individuals, Families and Communities**
- **Using What You Need**
- **Shifting the Power to What Works**

Pathways Forums were held throughout the state to gather input on these major themes from families and people with I/DD. Next, Hoosier leaders came together to form the **Indiana Response Team**, taking this wealth of information to develop key goals and action steps to achieve the desired result—a system to better serve Indiana's citizens with intellectual and developmental disabilities and their families.

Months of hard work has come together to provide a transformational plan, a *Blueprint for Change*.



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We Can Do Better



In these difficult times, there are many voices telling us what we can and cannot do. Some tell us to step back and simply accept gray days of austerity. But as our founders taught us—those parents of children with intellectual and developmental disabilities who joined together in 1956

determined to build a better and more accepting world for their children—we can and will continue to build that better world.

We can build a community that invests in families and supports their loved ones, brings help to people when they need it, keeps families together and builds community.

We can build a system that does not just look to government for all the answers, but helps families and people with disabilities help one another—a system that asks for responsible use of public resources, but in return empowers individuals

to use those resources in ways that best helps them as an individual, as a family and as a community.

We can build a system that looks to righting wrongs rather than simply writing more rules.

We can build a system that rewards creativity and quality, provides a fair reimbursement to providers and supports direct care staff with a living wage.

We can build a system designed for this century that uses technology, embraces and rewards new ideas and replaces models of the past with modern approaches.

A Time for Bold Action

The stakes are higher than at any time in our past. The status quo cannot be maintained. True reform and progress will not happen by simply nibbling around the edges. *Now* is the time for bold action.

In this issue of *The Arc News in Indiana*, we are excited to share key components of the *Blueprint for Change*, with you. We believe that this dynamic, and some may say controver-

sial, plan provides a pathway to begin making transformational change—today.

We are extending a special invitation to you to attend our 2011 Conference on Tuesday, November 1 at the Fountains Banquet and Conference Center in Carmel, Indiana.

Please join us on this important day where we will explore the **Blueprint for Change**, share why making transformational change is so important for so



many and seek your help, guidance and commitment to moving forward—together—in making positive change a reality for all.

Blueprint for Change

Guiding Principles

“We have a compass, few roads, but a good compass. The “We” makes the path: individuals, families, community, providers and state leaders.” — Big Minds Group

Building Career Pathways for All

Key Principles:

- ❖ Employment and work includes a range of options from full time employment with benefits to meaningful work as a volunteer
- ❖ Everyone means everyone, but does not mean the same thing for everyone

Discovering and Realizing Individual Gifts

Key Principles:

- ❖ Changing from a model based upon an individual’s deficits to a model that centers on an individual’s unique gifts
- ❖ Eliminating roadblocks that keep individuals from exploring their unique gifts

Supporting Resourcefulness of Individuals, Families, Communities

Key Principles:

- ❖ Changing Indiana’s high rate of out-of-home placements
- ❖ Redirecting resources to assist families supporting loved ones at home

Using What You Need

Key Principles:

- ❖ Actively encourage and educate families and people with I/DD how to control costs
- ❖ Redirect savings to those needing additional support and to those waiting for services

Shifting the Power to What Works

Key Principles:

- ❖ Do more of what does work and adds value
- ❖ Stop doing what does not work or does not add value
- ❖ Place both the control and the responsibility for the wise use of resources in the hands of families and people with I/DD
- ❖ Eliminate and reduce regulations which add costs, but do not add value

To Achieve the *Guiding Principles for Change*, We Must:

Create Cultural and Structural Change

Savings will result from effective implementation of change. Commitment will be required to strategically reinvest in new concepts supporting additional changes. Change will be necessary for everyone—advocates, families, people with I/DD, communities, government and funding sources. Stakeholders must interact in new ways to achieve the guiding principles.

Utilize Technology and Universal Design

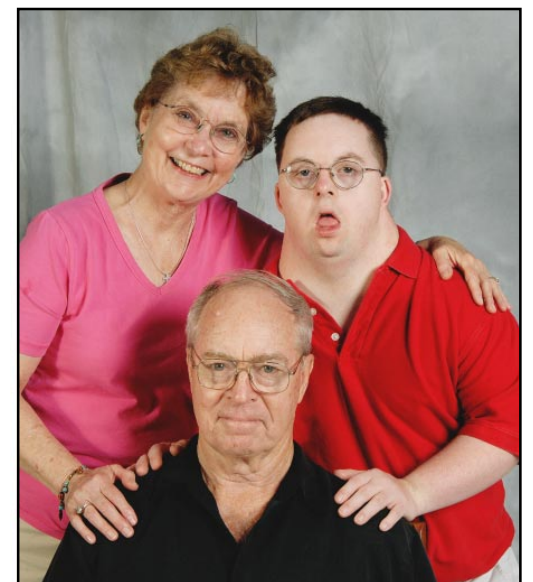
To achieve all of the guiding principles, we must utilize new technologies with consistent application by all stakeholders. Universal methods are necessary—from communicating with families and people with I/DD, to moving people through the bureaucracy, to connecting people with their friends, peers and community.

Build a New Language

To begin sharing a new vision, we must use terminology and apply terms that speak to the core philosophy of the guiding principles. The power of language cannot be overstated. It is people with I/DD who have moved us away from the “R” word, demonstrating that words do in fact shape perceptions and philosophy.

Shift Funding

Indiana has led the nation in redirecting public funding from institutional care to home and community supports. To achieve the Guiding Principles, a shift must occur again by redirecting resources and savings to individuals in need of additional help and to those who are waiting.





Cultural Change

“Major policy shifts must be made to make the development of Natural Supports part of people’s lives—making natural supports, and not just system supports, the option families see, while recognizing employment and natural supports are not enough for some and that an efficient, responsive and flexible system of paid supports will always be needed and utilized to provide the support people need—especially as life changes.” — Big Minds Group

The key to change starts with families and people with I/DD.

A shift in culture, beginning with families and people with I/DD, is needed to achieve the change envisioned. The shift must take place over time to allow families to understand and embrace a new way of thinking, for providers to adjust and for the system to evolve. There must be a long-term vision coupled with ongoing short-term strategies that move toward the Guiding Principles, but do not cause instability to a system already rocked by uncertainty.

Change will be viewed in different ways depending upon the life status of families and people with I/DD. Families with young children have very different goals than families in their 60’s and beyond. Cultural change must address different phases of families’ lives—those with young children, with children leaving high school, with children in their 20’s and 30’s, and families of adult children. In addition, respect and consideration must be given to the effects of poverty, unemployment and individual capabilities. Flexible approaches are necessary for families’ socio-economic differences.

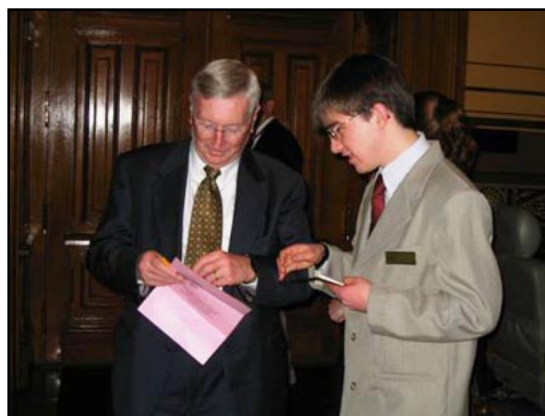


Structural Change

The financial processes and policies directing public resources are primarily driven by the state of Indiana. These governmental processes inherently drive the structure and direction for the I/DD community. Even though significant funding support comes from federal resources, the majority of policies affecting the I/DD community are controlled by the state, and that role may in fact increase given the current political climate.

Significant structural changes require cooperation and direction from state staff and policymakers, including legislators. Historically, those relationships have varied dependent upon the direction of the then-current administration. We must expect to achieve state funding goals, while guiding decision makers toward improving state supported services.

Our continued working relationship with the state will determine our success in achieving structural changes. We may encounter obstacles and naysayers. We must persevere.



Reinvestment of Savings and Strategic New Investment

To achieve this transformational change it will be essential to optimize the benefit from every dollar spent. All funds saved must be reinvested into the system to allow for continued change. This policy should be an incentive for families, self-advocates and providers, and policymakers who will see the impact of their investment multiplied. When new investment opportunities occur, decisions must be made strategically and follow a long-term plan with support by the state.

If families, individuals with disabilities and providers are to embrace transformational change, there must be clear intention to use money wisely, maximize the benefits as far as possible, retain savings within the system, and support the tremendous demands in new ways.

Laying the Foundation, Beginning the Change

"We must lay the foundation for a framework. It isn't about the money; it's about a culture shift."

— Big Minds Group

A member of the Big Minds Group, John O'Brien, talks about the situations people face and how systems must be built that support them.

Individuals have the "soft supports" of family, extended family and allies, and the community where they live. A successful system will help nurture and build those natural systems of support. Then it will utilize "hard supports" of government programs when appropriate. Too often the current system causes

individuals and families to jump right through those "soft" supports and go straight to supports that are both intrusive and expensive. In other cases, help is simply denied,

leaving people without support and in crisis.

The *Blueprint for Change* is designed to build a successful system that empowers people to shape their

own future, nurtures and creates natural systems of support, and strengthens the foundation of publically funded services for those who need those supports.

The Change Must Begin Today, But How?

Many actions will be necessary for change to happen. Sometimes we will need to take many steps at one time, while at other times, change will begin with one small step; but, change begins when you don't give in to those who tell you it can't be done. *This* is the history and promise of The Arc. In the words of the poet Marge Piercy:

It goes on one at a time.
It starts when you care to act.
It starts when you do it again after they said, "No."
It starts when you say, "We,"
and know who you mean,
and each day you mean one more.

The transformational change called for in the *Blueprint for Change* will not be easy and it will not happen through the work of The Arc alone. It will take many hands, joined together in a united effort for the *Blueprint* to move from paper to making a real and

meaningful difference in the lives of people with I/DD and their families.

Please join us at The Arc of Indiana's 2011 Conference, Appreciation Luncheon and Annual Meeting on Tuesday, November 1 at the Fountains Banquet and Conference Center in Carmel, Indiana, as we call on you to walk with us, hand in hand, to achieve the *Blueprint for Change*.

Learn more by visiting us at www.arcind.org or call us at 317-977-2375 or 800-382-9100.

Big Minds Group

John O'Brien and **Connie Lyle O'Brien**, Georgia—National experts on building community and community supports for persons with intellectual disabilities

Nancy Thaler, Washington, DC—Executive Director, National Association of Directors of Developmental Disabilities Programs

John Agosta, Portland, Oregon—HRSI, leading consulting firm on programs for people with intellectual disabilities

Tim Shriver, Washington, DC—President and CEO of Special Olympics

Serena Lowe, Washington, DC—Coalition leader working on self-determination in the District of Columbia and across the country

Tom Pomeranz, Indianapolis, Indiana—National speaker and consultant in the field of I/DD

John Lund, Seattle, Washington—Over his long career, John developed one of the most extensive industries programs in the country, and went on to led the way in making the transition to community based employment

Steven Eidelman, Dover, Delaware—Working throughout the world, Steve is one of the people in touch with emerging leaders in several states through his leadership series at the University of Delaware

James Toews, Portland, Oregon—A former Hoosier, James has been in Oregon for over 25 years and currently serves as Oregon's Assistant Secretary for Aging and Developmental Disabilities Services

Chester Finn, Albany, New York—Immediate Past President of SABE, Self-Advocates Becoming Empowered

David Mank, Bloomington, Indiana—Director of the Indiana Institute on Disability and Community and a national expert on employment of people with intellectual disabilities

Kathy Davis, Indianapolis, Indiana—Former Lt. Governor, Budget Director and Secretary of the Indiana Family and Social Services Administration Kathy's company, Davis Designs, has developed a world class simulation software program that provides real time assessment of strategies to help policy makers plan for the future

Mike Fodrill, Indianapolis, Indiana—President of the Board of Directors of United Cerebral Palsy of Greater Indiana and an active leader in the disability community throughout his adult life

Betty Williams, Richmond, Indiana—President of SABE and Consumer Education and Training Coordinator for The Arc of Indiana

Jeff Bassett, Howe, Indiana—Immediate Past President of The Arc of Indiana and active in his local Arc chapter, Arc Opportunities. Jeff and his wife Sue have an adult son with autism

Laura Vieck, Vincennes, Indiana—Vice-President of The Arc of Indiana, Chairman of the Pathways Committee, Mother to an adult son with Down syndrome

Kim Dodson, Indianapolis, Indiana—Associate Executive Director of The Arc of Indiana and The Arc's chief policy and legislative staff person

Jane George Surges, Indianapolis, Indiana—Facilitator of the Big Minds Group and Mentor in Residence at Butler University

Indiana Response Team

Jeff Bassett, Immediate Past President, The Arc of Indiana, Lagrange—Parent

Clint Bolser, CEO, Noble of Indiana, Indianapolis—Professional

Patrick Cockrum, CEO, Sycamore Services, Plainfield—Professional

Cheryl Crisp, President, ASK, Indianapolis—Parent

Lloyd Crowe, President, The Arc of Indiana, Lafayette—Parent

Kathy Davis, Indianapolis—Professional

Rita Davis, Noble of Indiana, Indianapolis—Professional

Bitta DeWees, Stone Belt Arc, Bloomington—Professional

John Dickerson, Executive Director, The Arc of Indiana—Professional

Andy Dietrick, Indianapolis—Parent

Connie Dillman, CEO, Tangram, Indianapolis—Professional

Kim Dodson, Associate Executive Director, The Arc of Indiana—Professional

Deb Easterday, President, The Arc of Greater Boone County, Lebanon—Parent

Mike Fodrill, The Arc of Indiana Board of Directors, Indianapolis—Self-Advocate

Shawn Fulton, Marion, SAI Board of Directors—Self-Advocate

Mike Furnish, CEO, Indiana Special Olympics, Indianapolis—Professional

Leslie Green, CEO, Stonebelt Arc, Bloomington—Professional

Teresa Grossi, IIDC, Bloomington—Professional

Carole Guess, Down Syndrome Indiana, Indianapolis—Parent

Jim Hammond, CEO, INARF, Indianapolis—Professional

Linda Hankins, Plainfield—Parent

Kelly Hartman, CEO, Insights Consulting, Indianapolis—Professional

Jeff Huffman, Chairman, The Arc of Indiana Education Committee, Noblesville—Parent

David Mank, IIDC, Bloomington—Professional

Shawn Rector, The Arc of Indiana Board of Directors, Lafayette—Self-Advocate

Donna Roberts, Executive Director, United Cerebral Palsy of Greater Indiana, Indianapolis—Professional

Jane Ruff, CEO, Hopewell Center, Anderson—Professional

Willaine St. Pierre Sandy, Carmel—Parent

Tom Van Meter, CEO, Forte Residential, Kendallville—Parent/Professional

Laura Vieck, Chair, Pathways Campaign, Vincennes—Parent

Lisa Wells, Executive Director, Down Syndrome Indiana, Indianapolis—Professional

Betty Williams, President, SABE, Indianapolis—Self-Advocate