Creating Blue Space – The Intentional Act of Individualizing Supports

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Creating Blue Space is a story about caring people dealing with one of the most important challenges facing the field of DD:

How to reshape an organization with deep investments in serving people in groups to supporting individuals in self-directed arrangements as citizens of their communities?
• It underscores the powerful forces at work in the field of Developmental Disabilities.
• The narrative invites others to participate in the change journey to social inclusion from clienthood to citizenship.
• It is realistic about the challenges that will confront individuals, agencies and the system on their change journey.
• It presents positive and successful examples of changed lives in spite of highly constrained environments.

Why is The Creating Blue Space Story Important?
Our experience is of a world of turbulent and intense conflict and unsustainable systems. In particular:

- A frustration that social inclusion and full citizenship for persons with disabilities has been elusive and difficult to achieve.
- A context of increasing regulations, control, oversight, paperwork and cost cutting that restricts creative social action and innovation while there are calls for “transformation”.

**Blue Space is the calm, life sustaining, place in the eye of the hurricane**
• Explore creative ways to support people in living a life vs. simply experiencing programs.
• Identify personal and organizational capacities to co-create individualized support arrangements with individuals and families.
Movement Towards Individualized Supports

![Bar chart showing movement towards individualized supports over time]

- **1988**
- **2014**
- **Change**

- **5-8 People**
- **3-4 People**
- **1-2 Persons**
- **Self-Directed**

The chart illustrates the change in the number of people receiving individualized supports from 1988 to 2014, with a significant increase in self-directed supports.
Lessons So Far

• Bringing forth new support forms requires different thinking.
• Change begins with you.
• Focus on deepening relationships with everyone, especially individuals and families.
• The change that we are seeking is transformational & deep within our culture therefore it is unresponsive to rational and linear solutions.
• It requires the capacity to ambidextrously manage innovation and stability in your agency and your world.
• Evolving models of care to supports needs the nurturance found in blue spaces.
• Reforming Health Care and Building Inclusive Communities – Compatibility Check?

Bending the cost curve by managing care

Supporting real lives

Competing Commitments or the Classic Double Bind?
Sophie’s Choice: New Business Model or Social Innovation

**Health-Care Reform**
- Covered Lives
- Rate Rationalization
- Metrics & Analytics
- Allowable Services
- Provider Networks
- Capitalization & Risk Corridors
- Duel Eligible(s)
- Marketing & Enrollees
- Benefit Package
- Automated Information Systems
- Monitoring Outcomes
- Long Term Care
- Acuity Assessment

**Building Inclusive Communities**
- Deep Listening Practices
- Realigning Relationships with Individuals & Families
- Social Innovation
- Learning organizations
- Co-Designing & Co-Implementing Supports
- Budget Flexibility & Authority
- Community Development
- Life Style Supports
- Self-Direction
- Capacities & Gifts
What Motivates Your Change Imperative?

- The Mission and Strategic Agendas of Providers
- The State and Federal Policy Initiatives
- Negative Press About DD Providers
- The Threat of Audit or Legal Action
- The Interests of Individuals and Families
- Personal Commitment to Social Change
“Good news—I hear the paradigm is shifting.”
Seeking Good Form
The Four Primary Forms that DD Services Have Taken Over the Past 60 Years

- Institutional Care
- Managed Care
- Integrative Supports
- Community Supports

Brian’s Story Tracks the Evolving Developmental Disabilities System
Emerging Support Models Reflect Our Striving for the Wholeness of Our Communities

- We need institutions to care for special populations
- We need mechanisms to coordinate all the services for needy consumers
- We need circles to connect a person’s unique qualities to a community
- We need communities with capacities to socially include all its members
I’m a patient – cure me!

I’m a consumer – satisfy me

I’m a person – listen to me

I’m a citizen – include me

Evolutionary Voices
Our Assumptions About People with Disabilities

People with Disabilities are Tragic & Vulnerable

People with Disabilities are Consumers with Clinical Needs

People with Disabilities are Individuals with Capacities

People with Disabilities are Citizens

Our Design Responses

Create Special Institutions

Coordinate Care

Person-Centered Supports

Community Resources

The Outcomes that Emerge From Our Care and Support Designs

Personal Care, Activity, Housing

Plan of Coordinated Care, with Appropriate Levels of Service, Customer Satisfaction

Individualized Supports leading to job, home & relationship

Valued Roles – A Life of Distinction
Our Beliefs About People with Disabilities Influences How a Person We Support Experiences the Community

- Through a Window
- Part of a Programmed Activity
- As an Active Citizen
- Supported by a Circle

Community
ENTERING THE U

Creating Blue Space: Fostering Innovative Support Practices

How have you and your agency members OPENED YOUR MINDS to see from a new perspective? Who did you invite to join you in a learning journey? What was your calling?

Where did your learning journey take you? Who did you connect with in a different way to understand a different perspective? What did you observe?

What patterns of thought, feelings, attitudes, and action must be let go?

WHAT CRITICAL QUESTIONS are provoked by your innovation that your agency needs to struggle with? What strategies will you need to involve others to spread the innovation?

What are the CORE DESIGN ELEMENTS of your individualized support prototypes?

What are the newly emergent patterns or energies connected with your new vision?

How will the new patterns be enacted?

WHAT NEW PATTERNS do you want to generate?

Inspired by Otto Scharmer
Richard

.lives in his own apartment
.his yard has space for his garden and his “stuff”
.near us to visit everyday
.enjoys and has friends in the neighborhood.
.has his own small business
.volunteers
Learn about...
- skills
- identity
- challenges
- qualities

... IN THE PERSON

Explore...
- stores on the block
- economic opportunities
- recreation options
- transportation options

... IN THE NEIGHBORHOOD

Contribution to Community
Creating valued roles with support

Listen for...
- values & identity
- connections
- resources
- neighborhood ties

... OF THE FAMILY

Design Personal Supports...
- individualized support
- natural supports
- service coordination
- employment supports

... USING CREATIVE RESOURCES
You Got to Be Pretty Good to Shift Paradigms
"He tried to change horses in midstream."
Different Kinds of Change Require Different Levels of Response
TRANSFORMATIONAL CHANGE

LOCATING A VANTAGE POINT
(Increasing Awareness)

SCOPING OUT THE TERRAIN

WHACKING THE BUSH

DISCOVERING A WAY

ARRIVING AT OUR DESTINATION
And a vantage point to scope out the next journey

PREPARING FOR THE JOURNEY
<table>
<thead>
<tr>
<th>LEVEL ONE</th>
<th>ROUTINE PROBLEMS</th>
<th>REACTING TO EVENTS WITH QUICK FIXES</th>
</tr>
</thead>
<tbody>
<tr>
<td>LEVEL TWO</td>
<td>DEVELOPMENTAL PROBLEMS</td>
<td>REDESIGNING POLICIES</td>
</tr>
<tr>
<td>LEVEL THREE</td>
<td>TRANSITIONAL PROBLEMS</td>
<td>REFRAMING: VALUES AND ASSUMPTIONS</td>
</tr>
<tr>
<td>LEVEL FOUR</td>
<td>TRANSFORMATIONAL PROBLEMS</td>
<td>REGENERATING: SOURCES OF ENERGY</td>
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</tbody>
</table>
Transformation Starts With Listening Deeply to Families

Bureaucratic Listening

Administrative Listening

Communal Listening

Person-Centered Listening
Doug and Brian stayed at home vs. ICF Placement. This was the 1st of its kind support arrangement—modification of parent's house. Supported day activities out of the home—redirecting group habilitation funds to individualized supports. Volunteer at a day care connected to their neighbors.
Patients to Be Cured

Consumers to Be Habilitated

Person to Be Developed

Citizen to Be Engaged

Power-Over

Doctor/Expert

Teacher/Instructor

Coach/Facilitator

Power-Shared

Community Resource
Theresa’s Story Contains the Ingredients of an Individualized Support.
Theresa

supported Mom and daughter to continue to live together as the mother aged.
 assisted daughter to assume a valued caregiver role with Mom.
 continued to support the daughter in the apartment by partnering with extended family.
 starting to recreate in the community
Levels of Individualized Supports – Leveraging Change Through Design

Low – Working Within the Box of Legacy Services – Offering Menu Options

Medium – Taking the Box Apart – Redesigning and Reinvesting Legacy Services

High – Working Outside the Legacy Box – Co-creating with Individuals and Families
Elements of Individualized Support

- **Choice** (have options from which to choose)
- **Decision making** (have a role in making decisions)
- **Control** (have control over aspects of their life space and resources)
- **Involvement** (in the settings where they spend their lives and their community)
John and Emily

.supported John and Emily getting married.
.have a home of their own
.very involved in their church
.worked in a nursing home and a restaurant respectively
<table>
<thead>
<tr>
<th>Five Modes of Creating a Support Plan</th>
<th>Tell (Demand Compliance)</th>
<th>Sell (Seek Buy-In)</th>
<th>Test (Invite Response)</th>
<th>Consult (Request Input)</th>
<th>Co-Create (Collaborate)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does the plan or program already exist?</td>
<td>Yes, final form</td>
<td>Yes, final form</td>
<td>Draft form</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Who decides on the final plan, program, or supports?</td>
<td>Provider, state agency</td>
<td>Managed Care organization</td>
<td>Managed Care organization and individual and family</td>
<td>Individual, family and provider</td>
<td>Individual and family with provider</td>
</tr>
<tr>
<td>Communication Method</td>
<td>Top down transmission of information</td>
<td>Top down transmission of information</td>
<td>Top down and bottom up transmission of information</td>
<td>Negotiation and Dialogue</td>
<td>Deep dives and dialogue</td>
</tr>
<tr>
<td>Level of Engagement &amp; Commitment</td>
<td>Low</td>
<td>Low</td>
<td>Medium</td>
<td>High</td>
<td>High</td>
</tr>
<tr>
<td>Care or Support Model</td>
<td>Institutional Care</td>
<td>Managed Care</td>
<td>Managed Care</td>
<td>Integrated Supports</td>
<td>Community Supports</td>
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Can Anybody Identify with this: Changing a Tire While Driving!
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<th>Supporting Individual Growth &amp; Positive Work Community</th>
<th>Generating Learning &amp; Innovative Solutions</th>
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<tr>
<td>Creating and Coordinating Stable Management Platforms</td>
<td>Working with Key Stakeholder Difference – Managing Politics &amp; Power</td>
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**Ambidextrous Leadership**

**Technical and Adaptive Capacities**
Citizenship Outcomes Require the Capacity to Socially Innovate
Models of Care are Designed
For the Predictable

Support Models are Designed
For the Emergent

Consider the Differences
<table>
<thead>
<tr>
<th>Rational Plan</th>
<th>Strategic Marketing</th>
<th>Appreciative Inquiry</th>
<th>Social Labs</th>
</tr>
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</table>

**Evolving Change Management Approaches**
# Revealing Our Immunities to Change

## David’s initial immunity map

<table>
<thead>
<tr>
<th>Commitment</th>
<th>Doing/not doing instead</th>
<th>Hidden competing commitments</th>
<th>Big assumptions</th>
</tr>
</thead>
</table>
| To better focus on a few critical things:  
  - Delegate  
  - Clarify outcomes desired  
  - Accept different approaches  
  - Support small failures as learning  
  - Challenge the thought process and logic | I let new opportunities distract me, adding to my list. 
I accept more tasks and sacrifice non-work-related things. 
I don’t consistently balance time commitment to urgent and important rankings. 
I don’t ask people to help me. | (I fear missing a good opportunity. 
Falling behind.) I’m committed to being independent and capable of anything. 
(I fear letting my team down. If I put myself first, I feel guilty and selfish.) I’m committed to being selfless. 
(I dislike leaving boxes unchecked—it’s harder to drop something than just to do it.) I’m committed to always finding a way to get it done. | If I am dependent on others and unable to do many things well, I lose my self-respect. 
If I put myself first I’ll become what I dislike in others—superficial and trivial. 
If I don’t find a way to get things done, I’ll stop being valuable. |
Lingering Questions for All of Us

- How do each of us develop the capacities needed to generate strong support models?
- How do we relentlessly remain aware of our underlying assumptions that lead us to certain care and support models?
- What kind of outcomes are we intentionally seeking?
- What do we retain from the care models as we evolve to support models?
- What kind of relationships promote desired outcomes?
- How does the system become more aligned and friendly to support models?