



**This is Us**



## Healing Partnerships

Hand in Hand for Excellence in Medically Complex Care



Parents of children with special needs did not choose this life...

- Scared/Angry
- Lonely/Sad
- Frustrated/Stressed
- Have increases problems with family and marital functionality
- Disrupted parent-child relationships
- Financially Burdened
- Intimidated
- Mood Swings
- Confused
- Selfless
- Advocate/Warrior
- Uncertain
- Hopeful/Helpless

What Parents Want...

- Trusted Partnership
- Active Listener
- Empathy/Understanding/ Tender Support
- Shared decision making
- Uniqueness recognized and valued
- Practical Intervention
- Non-judgmental
- Expert contributor
- Time
- Affirmation/Praise

"Put the parents first, for it is their lives that have been changed."  
-Kristen Stumeler - PT (1993)

### Through the Eyes of Parents

<b>Editors (1993)</b>	<b>1994:</b>	<b>2001:</b>
<ul style="list-style-type: none"> <li>• Margret Gertels</li> <li>• Susan Edgmon-Levietan</li> <li>• Jennifer Daley</li> <li>• Thomas R. Delbanco</li> </ul>	<ul style="list-style-type: none"> <li>• Picker Institute opened research on patient centered care expanded.</li> <li>• Patients perspective is now one of the standard metrics of performance measured by health organizations.</li> </ul>	<ul style="list-style-type: none"> <li>• Patient survey shows: "We have a long way to go."</li> <li>• 40% of all patients say they did not have enough input about their care or treatment in a hospital.</li> </ul>

**GOAL - Transform our health care system into a real system that provides effective and compassionate care for everyone AND is a joy to work in.**

### Through the Eyes of Doctors

"The most effective way to reach a diagnosis is for doctors to become fully engaged with the total human presence."  
-Dr. Bernard Rown (2005)

"The patients don't care how much you know until they know how much you care."  
-Dr. John Lin (2015)

"Patients just want the REAL you! The competent and caring you who really listens with compassion. The real you that talks like a real person and answers people with the honest truth in words they understand. The you that treats them like family."  
-Dr. Pamela Wible (2015)

**PACER CENTER**  
CHAMPIONS FOR CHILDREN WITH DISABILITIES...

The Progress

The People

The Projects

1977 - 2018

[www.pacer.org](http://www.pacer.org)

**Pacer Mission Statement**

Enhance the quality of life and expand opportunity for children/young adults with all disabilities and complex health care needs and their families so each person can reach their highest potential.

**Progress**

**1977:**  
It started with an IDEA and two women who wanted to help families and children with disabilities understand their rights in the educational system

**45,341**

**39,342**

**134,252**

8,672

2.2  
MILLION

68,282

73

**The People**

**Parents Helping Parents**

- Multicultural staff
- 75 collective years working together as Champions for Children
- Approximately 100% of the Pacer Parent Advocates have experiential knowledge



**The People**

- Pacer Staff sit on local and national boards and participate on numerous task force teams collaborating for better health/educational outcomes.
- Educational background: education, medical, law, OT, marketing, journalism, business leadership, psychology



### Services Provided to Families

- Provide information about children/parent's rights
- Guide them on policy and procedure pertaining to better educational, financial, health outcomes for their child.

### Services Provided to Families

- Drop In's, Phone calls, Home visits
- Assist families with writing IEP, 504, IHP

### Services Provided to Families

- Free workshops all over the state and live streamed
- Symposium

### Services Provided to Families

- Medical/Healthcare resources
- Navigation of state, county, federal services and financial support

### Services Provided to Families

- Care Coordination
- Dispute resolution: Conciliation, mediation, facilitated IEP, Due process hearing

### Projects



## Health Information Center

Provide information resources and training to help parents navigate health care system and support options.

- CARE coordination
- Guardianship
- PART program
- TeleHealth/Telegenetics

## Health Information Center

- Medical transition
- Parent leadership training
- Medicaid/MN Sure
- 504/IHP planning
- Drop in's
- Effective communication

## Health Information Center

- Partnerships:
  - Region 4 genetics
  - MDH
  - DHS
  - Family Voices
  - MCH
- Presentations for families and professionals

## Mental Health Team

Assists parents of children/adolescents with mental health challenges

- Teach parents and adolescents advocacy skills
- Guide them through resources and support systems
- Help families develop strategies to support their child/adolescent in school, community and at home

## Simon Technology Center

Assistive technology to allow individual to be "handicapable"

- Free consultation service
- Leading library
- Website helping find, trade, sell equipment



## Simon Technology Center

- Adaptable devices:
  - Adapted motorized vehicles
  - Live scribe pen
  - Robots
  - Switch driven devices
- Workshops
  - Code class
  - EX.I.T.E class

## Bullying

National Bullying Prevention Center promoting health relationships in Minnesota & California

- 1.4M hits on their website in one year
- Innovative resources for students, parents and educators
- Teaching advocacy skills and legal options

## Bullying

- Children with disabilities 2 to 3 times more likely to be bullied
- October is Bullying Month

Wear ORANGE in support of Bullying Prevention



## Puppets

Life size, multicultural, handmade puppets teaching tolerance and inclusion



- Teaching elementary and pre-school kids about disabilities
- Scripts and puppets sold all over the world
- Interactive opportunity to ask puppets and staff questions

## Federal Parent Training/Education

Teaching parents how to understand and navigate the education system – public and private.

- Provides individual assistance, training and resources for parents and professionals
- Work with multicultural families in their communities and education systems
- Teach advocacy and leadership skills

## Federal Parent Training/Education

- IEP's, 504 construction guidance
- Workshops, mediations, conciliation meetings
- 11,421 calls for help last year

## Transition

National Parent Center for Transition and Employment

Focuses on adolescents transition after high school into college, employment, housing, community and adult health care

- Assistive technology
- Social media
- Workshops, livestreaming
  - Interviewing, job search
  - IEP for transition

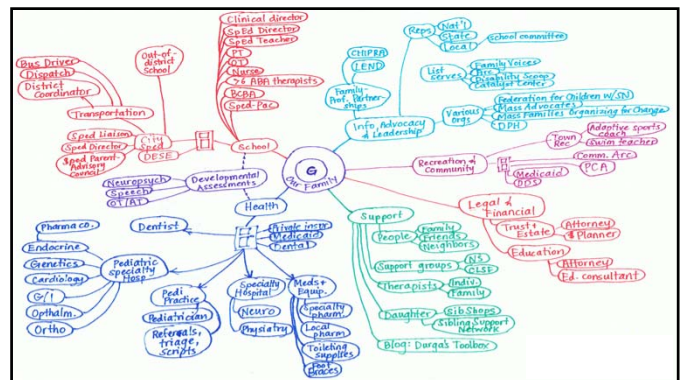
## Transition

- Housing conference
- Website, handouts, videos, tools
- Guardianship, SSI

## Populations

Chronological vs. developmental age

- Medically complex/fragile: pediatric-oriented medical problems
- Need to transition, ready & capable
  - Guidance and practice
  - Self determination, maturity
- Autism
- Mental illness



## Medical Transition

Parent's Perspective: Provide coordinated uninterrupted and patient-centered care

- Challenges:
- Transfer vs. transition
  - Financial issues:
    - Type of health care coverage affects utilization

## Medical Transition

- Challenges:
- Policy Changes:
    - Pre-existing conditions
    - Dependent coverage
  - Childhood diseases: adult practice
  - Pediatric hospital vs. adult hospital

## Medical Transition

### Challenges:

- Long patient-centered relationships with pediatric team
- Adult/Family practice specialists not comfortable or won't take complex young adults
- Med-Peds Doctors – not enough



Let's be a community of change



The image shows a close-up of several hands of different skin tones stacked on top of each other in a supportive gesture. The text "Let's be a community of change" is overlaid in white on a red, semi-transparent background.



Be passionate every day



The image features a bright yellow, round, smiling character with closed eyes, standing on a sandy beach with the ocean and sky in the background. The text "Be passionate every day" is overlaid in white at the bottom.

Donate/volunteer at PACER so we continue offering all of these free services to families



The image shows a blue sign for the PACER Center. The sign reads "PACER CENTER" in large letters, with "CHAMPIONS FOR CHILDREN WITH DISABILITIES" in smaller letters below it. The sign is set against a background of a building and greenery.



