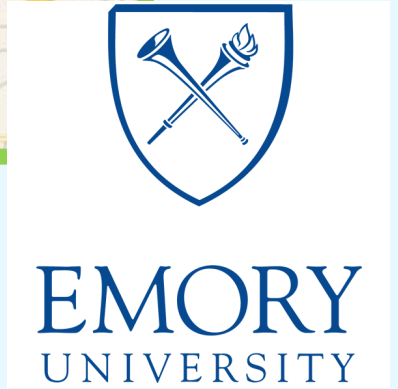




Roadmap to Research

Sharron Close, PhD, MS, CPNP-PC, FAAN
Emory University



Patient-Centered Inquiry: 2015-2018

“Nobody knows about us and nobody is interested in us”

Parent Participant 2015

We want you to ask us

- **What it is like to live this way**
- **What we want and need**
- **About our struggles**
- **How we can be involved in research**
- **How we can influence awareness**
- **Understand that we need your help now, not later.**

Qualitative and Mixed Methods Approaches

- ***Health Concerns of Women with Trisomy X***
Wei & Close 2018
- ***Adults with XXYY and Their Caregivers***
Close, Blumling & Martyn 2019
- ***For Parents: Understanding Non-Invasive Screening***
Dimonda & Close 2017
- ***Family Experiences Learning Diagnosis of X & Y variation in a Child***
Close, Riggan, Weinberg, Gross & Allyse 2019
- ***Relationship of Physical & Psychosocial Health on Quality of Life in Men with XXYY***
Blumling, Talboy, Martyn & Close 2019

Future Research Informed By Recent Research



- Mental Health
- Physical Health
- Social Interaction
- School Issues
- Transition from Childhood to Adulthood
- Independent Living
- Caregiver Issues

Focus and Expansion: Intervention Development

Mental Health

- Depression
- Self-Harm/Suicidality
- Anxiety
- Substance and Media Addiction

Physical Health

- Fatigue
- Pain
- Tremor
- Immunity/Inflammation
- Reproduction

Social Interaction

- Facial Expression Recognition
- Communication Interpretation
- Communication Reciprocity

More Intervention Development.....

Educational Issues

- Comparative Educational Approaches
- Comparative Educational Settings
- Teacher Trainings

Transition to Adulthood

- Transition Toolkit Development
- Pediatric and Adult Provider Trainings

Independent Living

- Toolkit Development for Independent Living

Support for Caregivers

- Physical & Mental Health
- Respite Care
- Promotion of Social Networking
- Telehealth Support

Mapping the Research Landscape

- Discovering and **deeply investigating the Problem**
- **Individual** Team Inquiry
- **Team Collaborations**
- **Growing the Research Enterprise**
 - ❑ Promoting “**Interest Contagion**”
 - ❑ **Attracting & Supporting New Researchers**
 - ❑ **Combine with Other Conditions** Sharing Overlapping Features & Problems

“Sometimes it is the people no one can imagine anything of who do the things no one can imagine.”

Alan Turing 1912-1954

Logician, Philosopher & Theoretical Biologist

YOU are those **PEOPLE**

Let your needs and ideas be known

Partner with clinicians and researchers

Participate in research: **Answers can be found there**

Help with getting others to participate in research