

## Journeys along the Continuum of Choice:

Access to Health Care Services among Families of Children with Special Health Care Needs

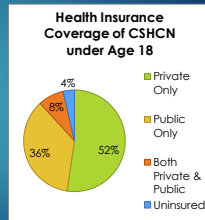
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I have nothing to disclose.

## Who are CSHCN?

- ▶ 15.1% of children in the United States are defined as Children with Special Health Care Needs (CSHCN)
- ▶ "...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998).



2009/10 United States National Survey of Children with Special Health Care Needs

## Background

- ▶ Accessibility and continuity of health-care services are a major concern for CSHCN
- ▶ CSHCN have a higher level of unmet needs for medical services that are generally linked to both poverty and insurance status
  - ▶ poor, near-poor, underinsured, and uninsured
  - ▶ socio-demographic differences, parent education and employment, literacy and language, and immigration and acculturation
- ▶ Formalized care coordination
  - ▶ Limited and rarely accessible

[Aday et al., 1992; Kogan et al., 2005; Kuhlthau, Nyman, Ferris, Beal, & Perrin, 2004; Mayer et al., 2004; Ngul & Flores, 2006; Newacheck et al., 2000; Yu & Singh, 2009]

## Background

- ▶ Increased difficulties navigating the health care system and accessing needed care, experiencing repeated attempts and failures to find appropriate medical and therapeutic services.
- ▶ Families are often left to fend for themselves, or "muddle through": using a variety of informal social support networks to help navigate and access health care, including family, friends and community members, and parent-to-parent support groups.
- ▶ Unstudied process that potentially has a great impact on the way in which families of CSHCN access quality, continuous, and coordinated care.

[Krauss, Wells, Gullely, & Anderson, 2001; Mayer et al., 2004; Pescosolido, Gardner, & Lubell, 1998; Warfield & Gullely, 2006]

## General Research Question

- ▶ *How do social networks, informal and formal, function to influence health care decision-making and ultimately facilitate or compromise access to health care services for children with special health care needs?*

### Investigate the concept of access from the perspective of a family of a CSHCN

- ▶ How do families understand the concept of access to health care?
- ▶ What does it mean?
- ▶ Is this concept similar to the understanding of access by others in their social network?

### Theoretical Framework Defining Access

- ▶ Andersen and Aday's (2000) Behavioral Model of Health Care Service Use
  - ▶ Rational choice
  - ▶ Potential vs. realized access
- ▶ Pescosolido's (1991) Network-Episode Model
  - ▶ "Muddling through" multiple routes with roadblocks and detours

### Methodology

- ▶ Non-probabilistic, purposive sampling technique
- ▶ 30 in-person qualitative interviews (60-90 minutes)
- ▶ Caregiver's illness narrative about child
- ▶ Hierarchical Mapping Technique (Antonucci, 1986)
- ▶ Thematic coding using Nvivo Software (QSR, 2010)
- ▶ Matrix analysis of substantive codes and social determinants
- ▶ Case comparative method

### Quota Sampling

CASES	Variable	Minimum # of Cases Required	# of cases sampled
CHILD AGE	Age 0-3	6	6
	Age 4-12	6	11
	Age 13-18	6	12
PARENT INCOME	Single/Married/Partner	6	10
	All Med Insurance	5	5
	Private Med Insurance	5	10
	Uninsured	5	7
GEOGRAPHICAL AREA	North-South-City	3	3
	North-South-Sub	3	4
	North-City-Sub	3	6
	South-City-Sub	3	7
	South-Sub-Sub	3	6
CHILD'S RACE/ETHNICITY	African-American	5	6
	Hispanic/Latino	5	14
	Other	5	5
PARENT EDUCATION	Less than high school degree	5	5
	High school diploma/GED	5	10
	College degree or above	5	20
CHILD'S HEALTH CONDITION*	Physical Health	5	10
	Psychological/Behavioral Health	5	12
	Special Health	5	6
	Medical Health	5	6
HEALTH INSURANCE	Child public health insurance	10	10
	Private health insurance	10	10
	Both private & public insurance	10	10

\*Note: One Hispanic child was adopted into one Hispanic white family.  
\*\*Note: Child may have more than one health condition

### Hierarchical Mapping Technique

**Types of Support**  
 Instrumental = S  
 Informational = I  
 Financial = F  
 Emotional = E  
 Negative

(Antonucci, 1986)

### Journeys along the continuum of choice

- ▶ Process-oriented conceptualization of health care access by CSHCN caregivers
- ▶ A continuum of choice bound by two endpoints that represent 2 ideal types
  - ▶ Limited choice access (N=14)
  - ▶ Open choice access (N=16)

← Limited ————— Open →

## Journeys along the continuum of choice

*A particular action, choice, or decision is embedded in a social process where the network interactions of individuals not only influence preference formation and define the situation but also drive the process of deciding whether something is wrong, whether anything can be done about it, what should be done, and how to evaluate results.*

Pescosolido (1992, p. 1104).

## Limited choice access (N=14)

Donna, the caregiver of a dually insured 14-year-old White girl with Von Willebrand disease, described her experience of choice during the process of obtaining access to care.

*Interviewer: And this particular doctor was just one from the practice?*

*Donna: Correct.*

*Interviewer: It wasn't somebody that you picked?*

*Donna: No, he was just one that had an opening and was able to get us in.*

## Limited choice access

Chen and Hua, parents of a publicly insured, 11-year-old Chinese boy with autism spectrum disorder, were referred to a developmental specialist by their son's pediatrician. Limited by financial, insurance, social isolation, and language constraints, Chen and Hua failed to get an appointment with a developmental pediatrician.

*It's hard to get in nowhere. I could not get it. Even the doctor tried to help us, a family doctor tried to help us find one, but it's hard to get in. They did not even accept a new patient.*

## Limited choice access

Jade, the mother of a publicly insured 17-year-old African American boy with schizophrenia, reflected on her experience accessing care for her son.

*It's like an HMO I believe and that means that we get—we get pretty good care. Even though people think it's really, really bad. But it's pretty good overall. You know you just have a couple of bad doctors out here. They aren't really willing to do their job and sometimes people need extra support or at least act like you care.*

## Open choice access (N=16)

Isabella, an adoptive mother/sister of a publicly insured 17-year-old Hispanic boy with neurofibromatosis, described her son's doctor with great assurance:

*Yeah, [Doctor]. We just got him. Because he was in the program, it was called the [Name of Program]. I'm not sure if you ever heard of that. That was the best program in the world.*

## Open choice access

Denise, the mother of a publicly insured 13-year-old African American girl with sickle cell anemia, also has sickle cell anemia herself. She sees the same hematologist as her daughter.

*Denise: I had, I already was going to [a children's hospital]. So I actually took her to [a children's hospital].*

*Interviewer: To [a children's hospital]?*

*Denise: Yes. And she actually sees [Dr. Hematologist]. He actually used to be my doctor, so he was my doctor and now he's her doctor. And he raised me.*

## Open choice access

Jillian, another mother of a dually insured, six-year-old White girl with muscular dystrophy and seizure disorder, reported the process she underwent in getting the "best" doctor:

*...And I have a friend who is an epileptologist in [another state] and I was talking to him about this and he said Jillian you've really got to see more of a specialist than a pediatric neurologist. You've really got to go to an epileptologist. And let me tell you who the best person in your area is. And he did that for me, I was able to see that person fairly quickly because I had a recommendation from another epileptologist.*

## Moving from limited to open choice access (N=7)

Margie, the mother of a dually insured seven-year-old girl with autism spectrum disorder (ASD), initially sought care at the nearby primary-care pediatrics clinic. Discussing the initial "limited choice" access in her case, she described having her daughter seen by various physicians within one practice:

*And again these doctors, they never sought a second opinion because she was being seen by three to four different doctors at the clinic. And they were all at the same clinic.... Yeah so I thought we were getting second and third opinions. So I continued to trust the doctors....*

## Moving from limited to open choice access

*The referral came rather easily because the speech therapist and I, we were on the same page pretty much from day one and she wasn't allowed to tell me—you know give me a diagnosis or anything but when I opened my mouth and said I think my child has autism, then she was able to go on and give me like internet sources and printed materials and leaflets and what not. So she gave me the referral to the doctor and she warned me that it could take as long as six to eight months to be seen...*

*Her name is [behavioral pediatrician] And we felt really comfortable going to her because we had—we did a little research and we learned that she's actually quite renowned and quite skilled in her area.*

## Social Determinants of Access

- ▶ **Income:** Below median caregiver income more prevalent in "limited choice" access group (N=9).
- ▶ **Education:** 15 or 16 caregivers in "open choice" access group had a college degree or more.
- ▶ **Ethnicity:** Minority and non-ESL caregivers were more prevalent in "limited choice" access group (N=9). White caregivers were more prevalent in the "open choice" access group.

## Social Determinants of Access

- ▶ **Illness acuity:** Caregivers of children with high-illness acuity requiring intensive care and hospitalization were more common in the "open choice" access group (N=13).
- ▶ **Insurance status:** Caregivers of publicly insured children were more prevalent in the "limited choice" access group (N=8). Caregivers of privately and dually insured children were more prevalent in the "open choice" access group (N=11)

## Discussion

- ▶ Vulnerable populations adapt to the state of being without power.
- ▶ Some caregivers simply do not experience a problem with access because they know of no other experience.
- ▶ As caregivers become more knowledgeable, conscious, and empowered to advocate about choices, they are more likely to be in or move towards "open choice" access.

(Gaventa, 1980).

## Conclusion

- ▶ Alternative process orientation to health care access.
- ▶ Range of family expectations and experiences of accessing services in the U.S. health care system.
- ▶ Emphasis of preconceived ideas and notions related to health care quality, provider familiarity, and trust in the health care system influence access and conceptions of choice.
- ▶ Caregiver perceptions and expectations of health care access are conditioned by specific experiences.
- ▶ Prior experience create expectations that shape what caregivers think their choices should be.

## Significance

- ▶ Contextualization of access demands that researchers think more about how they understand and operationalize "access."
- ▶ Limitations to content validity of larger studies measuring access as a dichotomous variable.
- ▶ Example of how embedded perceptions and experiences within social networks serve as links to access to health care services.

THANK YOU!!!!

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