Exploring Legal Consciousness:

Experiences of Families Seeking Funding for Assistive Technologies for Children with Disabilities

Denise Frankoff M.A.CCC-SLP, Ph.D.

November 18, 2010
Presentation Outline

- Purpose and Thesis
- Research Questions
- Research Methodology, Design and Analysis
- Results
- Conclusions and Policy Implications
- Discussion
Purpose of the Study

- To explore families’ experiences with the law and perceptions of the law as they seek funding for speech generating devices (SGDs) for their children who have severe communication impairments
- To examine how law on the street compares to the formal law
Barriers to Funding

- No health insurance
- Insurance does not cover SGDss
- Limited personal funds
- Complex and ambiguous health care laws and regulations
- Complex and ambiguous education laws and regulations
- Limited awareness, experience, and access to SGDss
- Cultural and linguistic differences among families and providers
SGD Funding Disputes: Case Law

- Few disputes involving SGDs have reached the courts
  - 6 reported cases involved Medicaid
  - 1 case involved a public school/IDEA
- No reported cases involved the intersection among IDEA, educational institutions, and health insurers
- Know little about funding disputes
Thesis

- Must look beyond formal law to examine legal disputes concerning SGD.s
- Peoples’ experiences with law in their daily lives shape their perceptions of their legal rights as they seek funding for SGD.s
- Perceptions may influence whether and how people claim rights and entitlements.
Research Questions

- As families seek funding for SGDs, how do they think and act in relation to the law?
- What are their experiences and perceptions about the law and how do those compare, if they do, to families’ rights and entitlements under the law?
Additional Questions

- What are families’ perceptions of their legal entitlements?
- How do families obtain their knowledge about the law?
- What experiences do they have with the law?
- In what ways does the law help or hinder a family?
- Are there similarities and differences among families in terms of strategies for achieving a positive outcome?
Questions (continued)

- Do families talk about whether ethnicity, economic status, level of education, gender and/or primary language affect their experiences? If so, what role do families perceive these factors play?

- What are the funding outcomes? How do the outcomes compare with the positive law and to the families’ perceptions of their entitlements under the law?
Legal Consciousness
Beyond the Boundaries of the Formal Law

- How people think and act in relation to the law in their everyday lives
- Broadens the focus of law from a static to dynamic process
  - Social networks, cultures, organizations and personal resources may shape perceptions
  - Complex and variable nature of the law
Research Methodology

- Grounded theory (Glaser and Strauss (1967))
  - Inductive method
  - Qualitative strategies which explain the ways people construct meaning in their lives
    - emphasize an analytic process
    - data is described, defined, categorized and coded
    - theories emerge and are refined over time

- Examine a dynamic process
  - data are the reconstruction of experience
  - well suited to study legal consciousness
Narratives of Law

Stories of law with a normative component
- Past events and characters
- Temporally-ordered events
- Relationship among events and characters

Describe beliefs about:
- the ways people should or should not act in relation to the law
- why the law should or should not be obeyed, resisted, or mobilized
- experiences with law that may reveal underlying disparities of power
Research Design

- Background legal research
- Telephone interviews: 2 Phases
  - Phase I
    - 23 participants – 20-30 minutes
      - Socio-demographic data
      - Funding vs. implementation ratings
  - Phase II
    - 10 participants – 2 hours
    - In-depth personal narratives
Recruiting Participants

- Assistive technology programs
- Parent advocacy organizations
- Augmentative communication user groups - listservs
Background Legal Research

- IDEA and state special education laws require school systems to provide speech generating devices and training as part of a Free Appropriate Public Education (FAPE)
  - Not required to fund devices if another public agency is obligated to do so
- Families must follow a complex set of procedures in order to attain rights under special education laws.
State Medicaid laws cover speech generating devices for eligible children as durable medical equipment.

State Medicaid waiver programs also cover speech generating devices.

Entitlements under private insurance vary depending upon the terms of the contract.
Narratives of Law: Data Analysis

- Early Stage
  - Prepared three case studies
  - Identified themes and categories; assign codes
  - Began matrices
  - Began to compare cases
  - Reviewed research questions

- Interim Stage
  - Completed additional case studies
  - Identified themes and categories; assign codes
  - Compared cases
  - Revised interview questions
  - Added and modified themes and categories; assign codes
  - Revised matrices
  - Began interpreting results

- Final Stage
  - Compared all cases
  - Completed interpretation
Results: Socio-demographic Data

- **Gender and marital status**
  - 23 mothers, 21 married and live with husbands

- **Geographic area**
  - Phase I – 13 states
  - Phase II – 4 states: MA, PA, RI, VA

- **Education**
  - Phases I and II
    - Most completed some college; 10 completed at least 4 yrs.; 6 had advanced degrees
  - Phase II
    - 5 completed 4 yrs., 3 had advanced degrees

- **Reported Annual Income**
  - Wide range
  - Phase II: from no reported income to $150,000, 3 declined
Funding Sources and Outcomes

- **All Participants**
  - Health insurance: 17/23
    - Medicaid program: 13/23
    - Employer-based: 4
  - Public School: 5
  - County Fund: 1

- **Phase II**
  - Health Insurance: 7/10
    - Medicaid program: 5/10
    - Employer-based: 2
  - School: 4
Rating Degree of Difficulty: Funding vs. Implementation

- Funding was:
  - easier than implementation: 14/23
  - as difficult as implementation: 4/23
  - “easy” to “slightly difficult”: 16/23
  - “extremely difficult”: 2/23

- Implementation was:
  - “extremely difficult”: 12/23
How Parents Obtained Knowledge About the Law

- Other parents
- Vendors
- Advocacy training
- Health care professionals
- State Departments of Education
- Regulations
- Websites
- Books
- Legal advocates
Legal Consciousness

- Constructed and reconstructed in interactions with a variety of people
- Shaped by personal resources and social circumstances
- Reflected in what people said and did
- Infused within victories and struggles
- Varieties of legal consciousness
  - Not mutually exclusive
  - Situation dependent
Parents’ Perceptions Compared to the Formal Law: Health Insurance

- Confidence in benefit for SGD
  - Consistent with funding outcomes
- SGD covered under durable medical equipment category
  - Consistent with most health benefit programs
- Medicaid: payor of last resort
  - Consistent with Medicaid regulations
Parents’ Perceptions Compared to the Positive Law: IDEA

- Public schools should provide an assistive technology evaluation, devices and training to implement the devices
  - Consistent with IDEA and state special education regulations
    - Other public agency may also be obligated
  - No parent indicated that training includes the parents and other professionals on the IEP team
  - Type of device is determined by IEP team
    - Does not have to be state of the art
Independent Evaluations (IE)

- Two parents thought they were entitled to an IE
  - Consistent with IDEA and state regulations under certain circumstances
- Neither parent requested IE
  - Lacked confidence in the process
  - Perceived too many restrictions
    - Influenced parents’ decision to access health insurance to fund an IE
Access to School-Purchased Devices Outside of School

- 6 parents expressed concern about access to devices outside of school
- IDEA regulations and state regulations:
  - Decision made on a case-by-case basis
  - Influenced parents’ decision to access health insurance benefits
Individualized Education Program: Right to Reject

- Two parents stated they had the right to reject their child’s IEP
  - Consistent with IDEA and state regulations
- These two parents filed a formal complaint with the school district concerning their child’s IEP
  - Not implemented as written
  - Not appropriate for the child
Main Theme: Empowered by the Law

- Framework for envisioning rights, discussing rights and claiming rights
- Committed to the possibility that the law could provide justice and fair treatment
- Created a rights consciousness
Health Insurance: Themes

- Funding process
  - Orderly, predictable
  - Complex and difficult to navigate but worth it
  - Confidence in benefits
  - Easier than asking the school to provide it

- How perceptions evolved
  - Vendors and independent evaluators provided assistance with funding process
  - Stories from other parents
  - Prior experiences with health insurance
  - Prior experiences with school
Health Insurance (cont.)

- How did perceptions influence decisions and affect which rights parents asserted?
  - Most parents obtained independent evaluations funded through health insurance
  - Most parents used health insurance for funding
  - Half of the parents obtained speech-language treatment for AAC training outside the public school, funded through health insurance
IDEA: Themes

- Achieving Its Main Objective
- Potential to Resolve Grievances
- Up Against the Law
- Together with the Law
IDEA: Up Against the Law

- Not implemented as intended
  - Inadequate knowledge, training and resources
- Complex, ambiguous, arbitrary
- Disparity in power and influence
  - Parents vs. the “experts”
  - Fear of retaliation
  - Distrust
- How perceptions evolved
  - Persisting disputes with speech pathologists, teachers, public school administrators
  - Stories from other parents
  - Personal factors
Up Against the Law: Parents Respond

How did parents respond?

- Engaged with variety of people
- Used informal dispute resolution strategies
- 3 invoked the formal law
  - Each prevailed
- Went outside IDEA and public school to obtain services
Dispute Resolution Strategies

- **Relational**
  - “They need to provide it because this is what he needs… “I know… I think… I believe…”

- **Rule-Based**
  - “IDEA 300.6 says that AT services include training the child, family, teachers and therapists.”

- **Factors**
  - Personal factors, social circumstances
  - Gender
  - Interactions with people
    - What other people said and did
Together with the Law

- Collaboration and cooperation
  - Focused on building relationships
- Personal factors and social circumstances
  - Professional background
  - Ties to the community
Conclusions

- Interactions shaped legal consciousness, in combination with personal factors and social circumstances
- Several themes were identified
  - Not mutually exclusive
  - Situation specific
  - Not exclusively legal
- Overarching theme: empowerment
Exploring the Gap between Formal Law and Law in Action

- Mastering the health insurance funding process – empowered by stakeholders
- Parents see legal claims in broad, normative terms rather than specific entitlements
- Procedural vs. substantive provisions
- Disparity in knowledge, power and influence
- Personal factors and social circumstances
- Relational vs. rights perspective
- Consistent with socio-legal research
Policy Implications

- **Families**
  - Empower to determine funding options
  - Enhance understanding of challenges
  - Encourage networking with community of parents

- **Speech-Language Pathologists**
  - Advocate for work-load analysis vs. caseload analysis

- **Legal Advocates**
  - Enhance understanding of challenges
    - Tailor advocacy to needs of family
Policy Implications

- **Vendors**
  - Encourage to assist families and educators with implementation

- **School Administrators**
  - Encourage needs assessment
  - Identify local and national resources

- **Sociolegal scholars**
  - Encourage researchers to study the intersection of special education law and health insurance
Policy Implications (cont.)

- Policymakers
  - American Speech-Language and Hearing Association
    - Standards for training, certification and licensing
  - Teacher Certification Boards
    - Teacher preparation, training and certification
  - State Assistive Technology Programs
    - Collaborate with school districts
Limitations of the Study

- Sample size
- Homogeneity
Directions for Future Research

- Larger and more diverse group of parents
- Perceptions of other stakeholders
- Factors that promote and hinder implementation
- Impact of web-based communication
- Speech-language pathologists and AAC competency
- Advocacy training programs
Directions for Future Research (cont).

- National Association of State Directors of Special Education
  - Analyze assistive technology guidelines and implementation
- State Assistive Technology Programs
- American Recovery and Investment Act of 2009 appropriated funds for AT
  - Analyze how funds were allocated and used
Final Remarks

- Study illustrated how law in action compared with the formal law and reasons for the gap
- Encourage other researchers to explore the legal consciousness of people who work with children with disabilities
- Improve the lives of children and their families
Thank you!!

Questions and Discussion