

Needs Assessment of Virginians with Spinal Cord Injury

Community Grants Colloquium
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Overview

- Importance of the project
- Qualitative Assessment
 - Methodology
 - Themes
- Registry update
- Quantitative Assessment
- Next Steps



The Project

Multi-method needs assessment of Virginians living with SCI, and their family / caregivers.

- Importance
- The collaboration
- Issue of culture

Qualitative Methodology

Focus Groups and Semi-Structured Interviews

- Location
- Facilitators and Interviewers
 - Who are they?
 - Training
- Content
- Participants
- Advisory Board
- Consultants

Location

- Conducted in homes or public settings
 - Accessibility
 - Convenience
 - Comfort

Facilitators and Interviewers

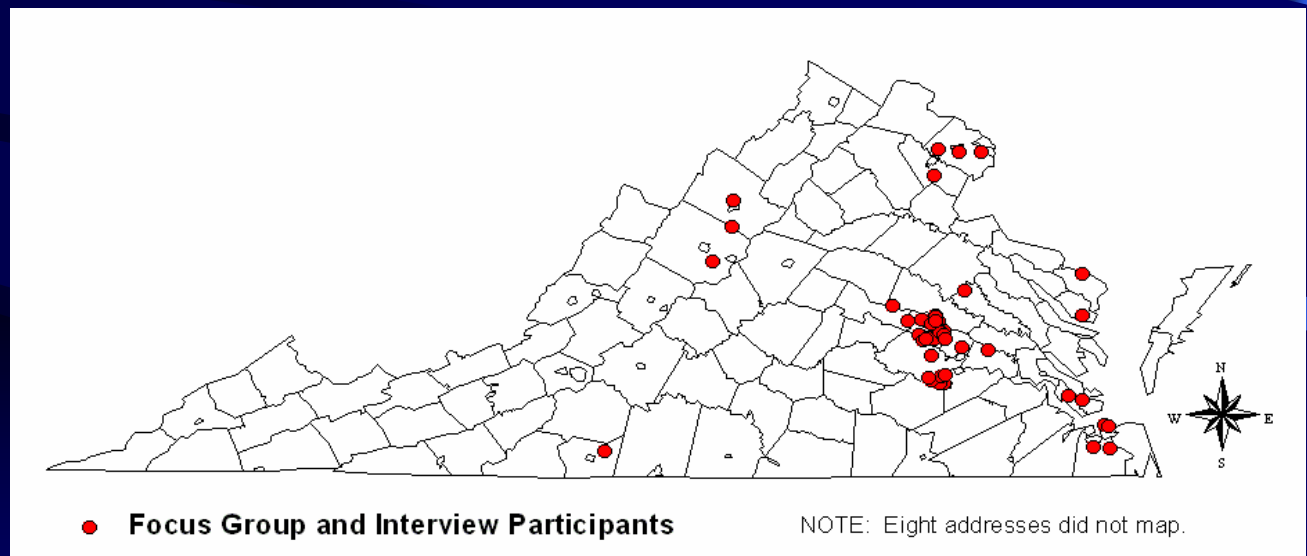
- Graduate students and members of the research team
- Training sessions, pilot focus group

Content

- Eight Areas of Focus
 - Motivation to participate
 - Challenges
 - Strengths / Resources
 - Relationships
 - Employment
 - Health Care
 - Discrimination
 - Other information

Participants

- 66 individuals with SCI
 - 23 White women
 - 6 African American women
 - 32 African American men
 - 2 Asian men
 - 1 Latino
 - 1 Latina
 - 1 Bi-racial
- 8 Family Members / Caregivers
 - 1 African American man
 - 3 African American women
 - 4 White women



Strengths

- God
- Family
- Peers
- DRS counselor
- Finding a purpose / a reason
- Support group: family & friends and their attitudes
- Attitude
- Anger / “I’ll-show-you” attitude Strong person
- Independence
- Patience
- Persistence
- Confidence
- Strength of will

Challenges

- Accessibility
- Other People's attitudes
- Transportation
- Housing
- Finding Resources
- Every day hassles
- Learning about injury
- Finding knowledgeable doctors
- Parenting
- Adapting to a new way of life / readjusting
- Learning to make the best of the situation

Work / Employment

- Desire to work
- Recognition of the social and psychological benefits of work
- Frustration with being in the house
- Desire not to be dependent on the system
- Importance of DRS counselors
 - Positive and negatives
- Role of Woodrow Wilson
- Fear of losing benefits
- Mistrust of System to work with them

Health Care System

- **Providers**
 - Physicians
 - Insensitivity
 - Need for partnership
 - Lack of knowledge about SCI
 - Lack of respect for what persons with SCI experience
 - Certified Nursing Attendants
 - Increasing standards for certification
 - Need for a review body and grievance procedures
 - Increase pay
- **Systemic Level Problems**
 - Insurance
 - Problems getting supplies, wheelchairs, etc.
 - Complications in negotiating the system
 - Long waits in hospitals

Discrimination

- Disability – related discrimination
- Long waits in hospitals and for office visits
- “Nurses and providers not wanting to touch you.”
- Pain management
- Assumption of blame or fault related to injury; violently acquired injury automatically associated with drug use
- Pessimistic comments about outcomes
- Observed disparities in quality of care and attitudes of health care providers and workers at social service agencies
- Disparities in quality of housing
- *“They drag their feet with the black folks. White folks can get anything they want. But the only way black folks can really get something, you got to know somebody higher up.”*

Issues and Concerns of Women

- Birth Control / Reproductive rights
 - Child birth
 - Parenting / child rearing
- Equipment not shaped for women's bodies
- Rehabilitation or recreation techniques designed for men and for individuals with good upper body strength
- Lack of role models or connection with other women with SCI / disability
- Unwillingness to ask questions because of fear of being seen as ignorant
- Sexuality

Qualitative Assessment

Issues and Challenges

- Recruitment
- How people racially identify
- Need for materials in Spanish
- Alternative language interviews
- Capturing voice when ESL is used

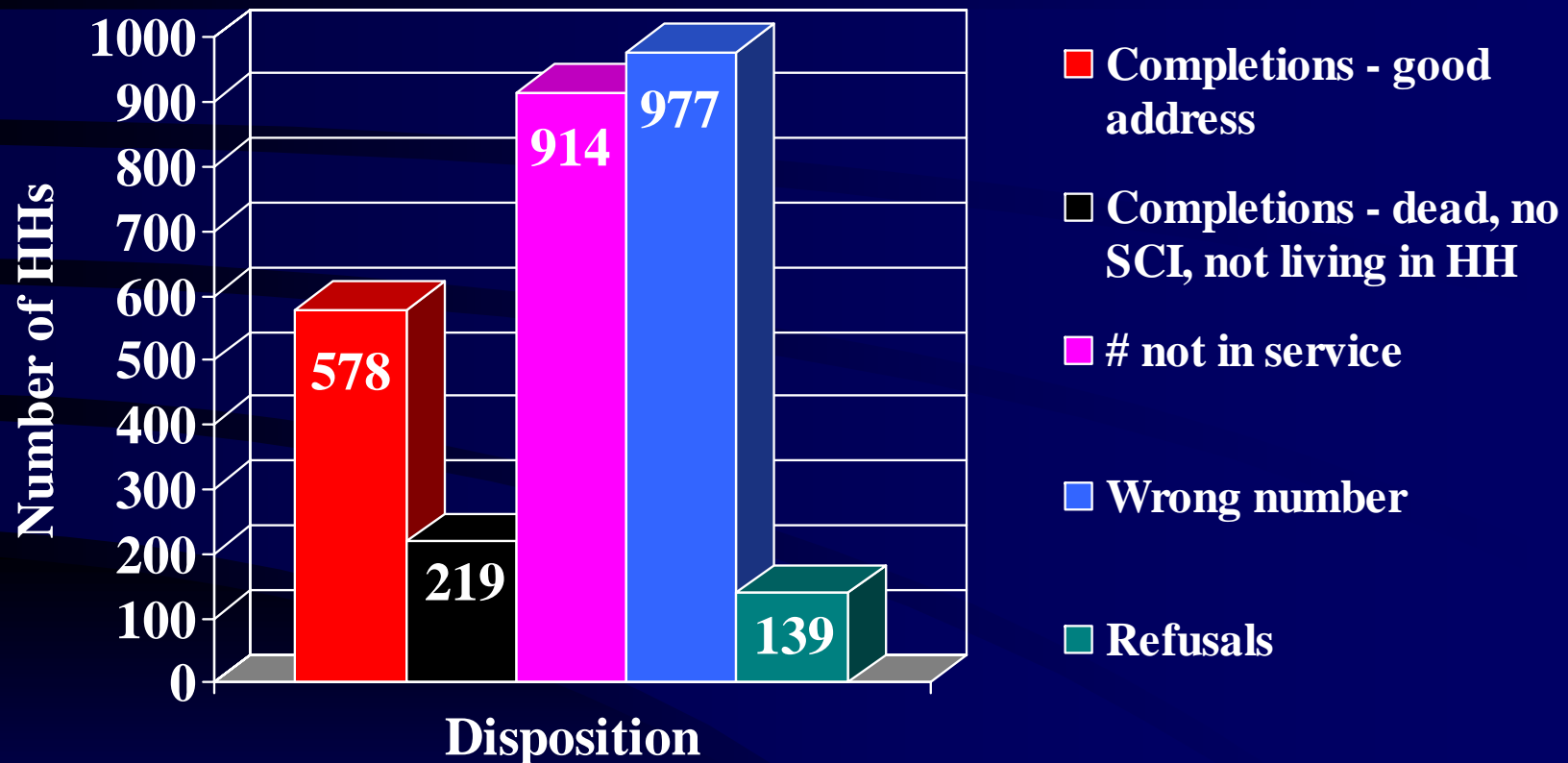
Suggestions and Recommendations

- Provide specialized training for physicians, health care providers, persons with SCI, and the general public
- Instill knowledge and address fear and biases
- Peer mentorship programs
- Information Clearinghouse
- Stem Cell research
- Improved standards or licensure for CNAs
- Create advocacy and support groups
- Grievance processes
 - CNAs, Insurance, accessibility, health care providers
- Respite opportunities for caregivers

Registry Update

- Following IRB approval, obtained copy of registry from DRS
- Initially planned on calling a random sample of individuals on registry to verify information
 - Many bad addresses on prior mailings using the registry
 - Used SERL in an attempt to verify the entire registry (n=3,258)
 - Prenote
 - Phone call

Summary of Registry Update Effort (Total Records = 3,258)



Bad adds sent to listcleanup.com (n=1,534)

- 939 “mailable” address returned
- 80 moved and had new “mailable” address

Quantitative Assessment

- Two surveys developed
 - Persons with Spinal Cord Injury
 - Family Members / Caretakers
 - Pilot Tested
- Spanish Translations
- Web-based Option
- Upcoming steps
 - Mailing
 - 2 wave with pre-note and reminder
 - \$3 incentive
 - Telephone Follow-up


SCI SURVEY - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Forward Stop Refresh Home Search Favorites

Address [Redacted] Go Links

Virginia Spinal Cord Injury Needs Assessment Survey



Map of Virginia showing major cities and geographical features. The map includes labels for neighboring states: Pennsylvania, New Jersey, Delaware, Maryland, Washington D.C., Ohio, West Virginia, Kentucky, Tennessee, and North Carolina. Major cities in Virginia are marked with red stars and labeled: Blacksburg, Roanoke, Lynchburg, Charlottesville, Richmond, Fredericksburg, Alexandria, Arlington, and Norfolk. Other locations include Shenandoah Nat'l. Pk., James River, Chesapeake Bay, Newport News, Portsmouth, Virginia Beach, and Bristol. Mountain ranges like the Allegheny Mts. and Appalachian Mts. are also shown.

Please click the "next" button to begin.

NOTE: If, at any point, you would like to stop the survey and return to it at a later time, click the "save" button at the bottom of the screen. Then, add the page to your "favorites" or "bookmarks".

Next Save

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Moving Forward

- Next Steps
 - Field survey
 - Reports
 - Training / Education of Health Care / Rehabilitation Professionals
- Clinical implications and taking action
- Additional research

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