The Rhode Island Special Needs Emergency Registry – An Opportunity for Expanding the Healthcare Provider's Role in Health Equity

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"Every American should have the opportunity to be as healthy as he or she can be. Every community should be safe from threats to its health. And all individuals and families should have a high level of services that protect, promote, and preserve their health, regardless of who they are or where they live."

— Trust for America's Health (TFAH)[1]

These insightful words provided by TFAH reflect Rhode Island's aspiration to achieve health equity, but require expansion to address health security. All citizens should have the opportunity to be healthy by accessing services regardless of who they are, where they live, and whether or not an emergency is happening. The American Medical Association's *Declaration of Professional Responsibility* references that the healthcare community, as a whole, takes ownership for safeguarding the health of patients who are under medical care to earn society's trust in the healing profession.[2] Thus, do providers inherently challenge themselves to consider what they can do for patients to also prevent health disparities from occurring during and after a disaster?

Rhode Islanders who report having a disability or diabetes are more likely to be prepared (25.1% and 26.2%, respectively) than those without a disability or diabetes (18.3% and 19.2%, respectively).[3] The Federal Emergency Management Agency (FEMA) and Ad Council report 81% of Americans are not very prepared for an emergency,[4] increasing the likelihood for relying upon outside assistance. Being prepared should include having an emergency plan and an emergency three-day supply of water, food, and medications. Higher personal and community preparedness can minimize reliance upon first responders for the first three days after an emergency.

The Rhode Island Special Needs Emergency Registry (RISNER) was established in 2007 by the Rhode Island Department of Health (RIDOH) and the Rhode Island Emergency Management Agency. RISNER strives to identify individuals with disabilities, chronic conditions, or other special healthcare needs. Residents who use life support systems, have mobility or assistive devices, utilize a service animal, or require assistance due to cognitive/developmental needs are the primary focus. Residents of assisted living/nursing facilities are not eligible for enrollment since those facilities have trained medical staff and are already prioritized by first responders (e.g., police, fire, and emergency medical services).

Outreach has predominantly focused on community-based organizations, first responders, and individuals. The information within RISNER is kept strictly confidential at the state/municipal level. Data are only shared with first responders to assist in responding to 911 calls and with local/state emergency management staff to protect individuals' safety and well-being during emergencies. While enrollment in RISNER does not guarantee assistance, the system allows first responders to effectively plan for, prepare for, and respond to community needs. This article briefly describes the demographics of enrollees and recommends ways RISNER can be utilized as a tool for healthcare providers seeking to protect and prepare their patient population.

METHODS

RISNER data are updated through an annual mailing to all enrollees in addition to reconciliation with the Center for Vital Records. Incomplete data due to self-registration utilized for enrollment can occur. A dataset containing 14,836 individuals enrolled in RISNER as of December 31, 2015 was updated to remove individuals with either an invalid year of birth (<1903) or a missing date of birth to standardize association of disability data to age groups. The data presented herein were gathered from a one-page enrollment form containing 69 data entry fields. While RISNER prioritizes collection of predefined disabilities important to consider during emergencies, individuals can enter "other disabilities" using text boxes on the enrollment form. Individuals enrolled with only "other disabilities" reported were excluded. A total of 13,175 enrollees were reviewed, grouped, and analyzed using SAS® 9.3.

Demographics were grouped, where applicable, for ease of comparison. Grouping included core cities (i.e., those with highest childhood poverty levels) versus non-core to compare geographic enrollment. **Table 1** illustrates the fields combined for this report using the available data entry fields. These fields were used to generate 13 traits that were then consolidated to create six major characteristic variables. These were utilized to create three main categories (i.e., mobility, life support, and sensory/cognitive) for the disabilities/conditions. The number of categorical disability types selected by an enrollee was also calculated as having a single category, two categories, or all categories.

Table 1. Disability Variables

Category	Characteristic	Trait	Field(s) combined
Mobility	Uses Assistive Aid	Mobility Device	Uses Wheelchair/Mobility Vehicle Uses Walker/Cane Uses Crutches
		Prosthetic Device	Uses Prosthesis
		Assistive Animal	Uses Assistive Animal
	Confined to Bed	Confined to Bed	Is Confined to Bed
Life Support	Dependent on Mechanical Device	Oxygen / Respirator / Ventilator	Uses Oxygen Uses Tanks Uses Concentrator Uses Respirator/Ventilator Has Battery Backup for Unit
		Pacemaker / Defibrillator	Uses Electrical Uses Pacemaker Uses Defibrillator
	Dependent on Treatment	Insulin	Is Insulin-Dependent
		Dialysis	Uses Dialysis On Dialysis at Home On Dialysis at Clinic
Sensory/ Cognitive	Has Sensory Impairment	Auditory	Is Hard of Hearing Is Deaf Uses Hearing Aids
		Visual	Is Visually Impaired Is Legally Blind
	Has Cognitive/ Muscular Condition	Neurological Disorder	Has Seizure Disorder Has Autism Spectrum Disorder Has Alzheimer's/Dementia Has Cognitive/Developmental Delay
		Speech Impairment	Is Speech Impaired Has Non-Verbal Impairment
		Psychiatric Disorder	Has Psychiatric Condition

Table 2. Demographics by Age, Race, Language, and Location, 2007–2015

Total Sample	N	%
	13,175	100
Age		
Children	871	6.6
0–6 Years	168	1.3
7–17 Years	703	5.3
Adults	12,304	93.3
18–24 Years	427	3.2
25-44 Years	1,257	9.5
45–64 Years	3,239	24.6
65 Years and Older	7,381	56.0
Race		
Single Race	11,666	88.5
White	10,225	77.6
Non-White	1,441	10.9
Multi-Race	644	4.9
Unreported Race	865	6.6
Preferred Language		
English	11,992	91.0
Non-English	1,145	8.6
Spanish	741	5.6
Portuguese	150	1.1
Other	254	1.9
American Sign Language	38	0.3
Living Location		
Core Cities	3,701	28.1
Providence	2,141	16.3
Pawtucket	802	6.1
Woonsocket	518	3.9
Central Falls	240	1.8
Non-Core Cities	9,474	71.9

Note: Additive values of groups are not exact due to rounding percentages.

RESULTS

Table 2 describes the overall composition of RISNER enrollees' demographics collected on the registration form. The majority of enrollees (77.6%) reported their race as white, 10.9% as non-white, 4.9% as multi-racial, and 6.6% did not report race. Similarly, a total of 91.0% of enrollees indicated a language preference for communications or assistance in English, with 9.0% indicating a language other than English. Enrollees spanned across the age spectrum from birth to over 100 years of age (data not shown). Only 28.1% of enrollees reported living in core cities that include nearly two-thirds of the state's poor children.

Table 3 depicts the categories, characteristics, and traits of disabilities identified. A total of 42.3% of enrollees identified only one disability-type, with sensory/cognitive being the most common (21.0%). A similar percentage (40.3%) of enrollees identified themselves as having two disability-types, with mobility and sensory/cognitive being the most frequent combination (21.9%). Only 17.9% of enrollees identified as having all three types. Over one-third of individuals reported at least one of the following characteristics: uses assistive aids (53.8%), has sensory impairments (40.0%), or has a diagnosis with cognitive/neurological conditions (35.9%). In terms of characteristic-specific traits, the use of a mobility device (53.2%), dependency on pulmonary devices, such as oxygen or a respirator (13.3%), or diagnosis with neurological conditions (28.9%) were most common.

Relationship status of the registrant to the enrollee is outlined in **Table 4**. Self-enrollment was most common (69.0%) followed by enrollment by a personal contact (21.7%). The lowest registrants were service providers (9.2%), where only 1.0% of enrollments were represented by healthcare workers. The remaining 8.1% of service providers were social workers/case managers.

Table 3. Enrollment by Disability Variables, 2007–2015

Total Sample	N	%
	13,175	100
Disability Category		
Single Disability-Type	5,508	42.3
Mobility	1,395	10.6
Life Support	1,410	10.7
Sensory/Cognitive	2,703	21.0
Two Disability-Types	5,304	40.3
Mobility & Life Support	1,355	10.3
Mobility & Sensory/Cognitive	2,884	21.9
Life Support & Sensory/Cognitive	1,065	8.1
All Disability-Types	2,363	17.9
Mobility Characteristics		
Uses Assistive Aid *	7,091	53.8
Mobility Device	7,012	53.2
Prosthetic Device	209	1.6
Assistive Animal	69	0.5
Confined to Bed	399	3.0
Life Support Characteristics		
Dependent on Mechanical Device *	2,343	17.8
Oxygen/Respirator/Ventilator	1,749	13.3
Pacemaker/Defibrillator	796	6.0
Dependent on Treatment *	2,271	17.2
Insulin	1,360	10.3
Dialysis	1,143	8.7
Sensory/Cognitive Characteristics		
Has Sensory Impairment *	5,270	40.0
Auditory	3,281	24.9
Visual	3,086	23.4
Has Cognitive/Muscular Condition *	4,733	35.9
Neurological Disorder	3,810	28.9
Speech Impairment	1,658	12.6
Psychiatric Disorder	1,121	8.5

Notes: All trait percentages represent presence among entire sample size.
* Includes individuals who reported one, two, or all three traits within the denoted characteristic.

Table 4. Enrollment by Registration Method, 2007-2015

Total Sample	N	%
	13,175	100
Relationship To Enrollee		
Self	9,093	69.0
Personal Contact	2,866	21.7
Family/Friend	2,810	21.3
Caregiver	56	0.4
Service Provider	1,216	9.2
Social Worker/Case Manager	1,060	8.1
Healthcare Worker	128	1.0
Other Professional	28	0.1

DISCUSSION

Using the total number of enrollees (N=13,175), RISNER enrollment can be estimated at 1.0% of the state's population. Enrollment appears low compared to the U.S. Census estimate[5] (12.8%) and Disability and Health Program estimate (19.0%)[6] for the number of non-institutionalized Rhode Islanders with disabilities. Aside from lack of awareness, enrollment might be limited by a belief that preparing won't help.[4] A person's decision to not enroll may be based on one's perception of not having a disability or not needing assistance from others.

Increased outreach activity to raise awareness about RISNER and improve inclusion in the registry is needed. Outreach efforts that leverage the lowest registering groups (i.e., healthcare workers) may help diversify and increase enrollment. Primary care practices, select specialties (e.g., geriatricians, ophthalmologists, podiatrists), and health center providers may help to reach individuals who should be enrolled, regardless of age, language, race, or geography. As efforts are underway to reduce health disparities among Rhode Islanders already at-risk, healthcare providers can help us reach new audiences. The results from this article create an opportunity for healthcare workers to play a pivotal role for improving the resiliency of Rhode Island patients.

There are a few study limitations. Gender was unavailable for analysis because the default value for the field was previously set to female and therefore, cannot be validated. Trend data and a review of all enrollment/disenrollment data since inception could not be included given changes to the dataset resulting from technology improvements to RISNER. Form design limited the data set and how fields were merged into categorical variables. While RISNER data are updated through ongoing self-reports and annual matches to vital records, there remains a chance that a small data percentage may be attributed to deceased individuals.

MOVING FORWARD

In 2016, RISNER began improving data collection with a revised form that obtains information on enrollees' living situations, transportation access, and conditions such as morbid obesity. The intent of this first improvement is to allow for further analyses that can provide more detailed community profiles to local responders and emergency planners. Secondly, a shift in the outreach strategy for RISNER will be aimed at balancing enrollment across population groups. Targeted outreach in this manner aims to ensure

equal access to RISNER. By working together, public health and healthcare can safeguard the health of the population.

Eliminating current health disparities and preventing new disparities from occurring before, during, or after an emergency remains a strategic priority for RIDOH. Healthcare provider collaboration on the use of RISNER as a tool for helping Rhode Island assure health equity and security is feasible. Dialogues with healthcare providers on how to promote RISNER is a start. Providers can then enroll patients and provide informational resources to help improve personal preparedness among those with special healthcare needs. In addition, healthcare providers can partner with RIDOH as part of the local emergency management system that utilizes RISNER to conduct activities such as wellness calls before, during, and after an emergency. To enroll someone or learn more, visit: http://www.health.ri.gov/emregistry/.

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