KENTUCKY TRAUMATIC BRAIN INJURY HOUSEHOLD PREVALENCE STUDY
DRAFT FINDINGS

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The Trust Fund and Data Collection

KRS 211.474 includes the provision for the TBI Trust Fund board to:

"Investigate the needs of brain-injured individuals and identify gaps in current services."

Sources of Data that Respond to Mandates

1. **The annual *Traumatic Brain Injury and Spinal Cord Injury Surveillance Project* prepared by the Kentucky Injury Prevention Research Center at the University of Kentucky**
2. **Results of two major data collection efforts during SUMMIT meetings (1999 and 2001)**
3. **Consumer and family member surveys and focus groups**
4. **Management reports and ad hoc reports from Eckman/Freeman on service demand, use patterns, and costs of TBI benefits to persons using the Fund**

Surveillance Project

- **Combines data from hospital sources and CDC databases to arrive at estimates of the NUMBER of INCIDENTS of brain injury each year in Kentucky**
- **Provides important mortality information and data on causes of injuries from cites in medical records**

SUMMIT Meetings and Focus Groups

- Provide qualitative and limited quantitative data about perceived service gaps in Kentucky
- Identified and ranked service needs by general type of service
- Had the additional benefit of reaching a large number of consumers, family members, providers, and advocates

BACKGROUND TO TBI DATA COLLECTION

- All 50 states were surveyed to learn about the kinds of data that were being collected on brain injuries
- Three major types of data are collected:
  1. Trauma registries
  2. TBI registries
  3. Surveillance projects

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State TBI Data Collection Survey

- Contacts in each state were asked:
  - Does your state have a traumatic brain injury registry or surveillance system?
  - If so, does your state conduct follow-up surveys with those on the registry? Is the follow-up contact to gather further data about TBI or to provide educational and resource material?
  - How is your follow-up program funded?

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Resources Used for Information

- Brain Injury Association of America's listing of state affiliate contacts (www.biausa.org)
- State websites for BIA organizations
- Contact phone numbers/emails for state BIA offices
- CDC website (www.cdc.gov/ncipc)
- Neurotrauma registry website (www.neure.com)
- State Departments:
  - Health & Human Services
  - Public Health
  - Injury Prevention
  - Trauma and EMS Departments

State by State

- States monitor TBI incidence using either:
  - Data pulled from general trauma registry,
  - TBI surveillance system, or
  - Specific TBI registry
- Currently 88% of states have TBI registries *and/or* surveillance systems which monitor incidences of TBI as documented by trauma, hospital, death and other records.
- Only five states (CO, IA, OK, SC, and TN) conduct follow-up surveys to gather further data on TBI.

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TBI Surveillance Systems

- State surveillance systems vary in management and methods for collecting data
- They often include multiple data sources
- Sources of data are similar and commonly include:
  - Trauma registry data (if one exists)
  - Hospital and medical records
  - Cause of death records
  - Medical examiner reports
  - Transportation/ Collision records
- Mandatory reporting states require hospitals, ERs, and trauma departments send data to the surveillance system

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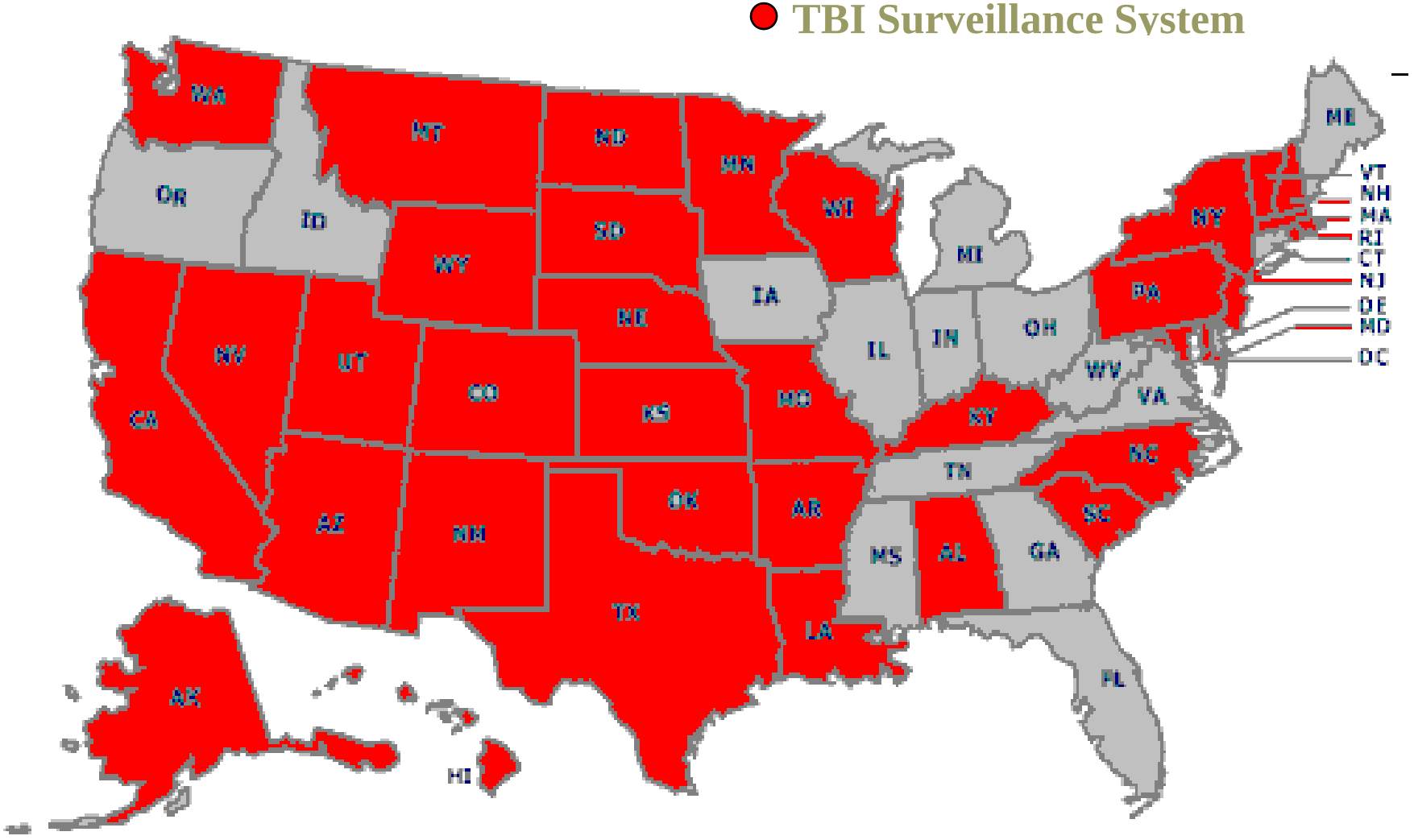
TBI Surveillance in 68% of States



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TBI Registries

- TBI Registries are mandatory in the majority of states that have registries
- Voluntary registries collect data from clients, families, and online surveys
- All registries collect incidence data and some combine the registry with Spinal Cord Injury data
- Follow-ups to collect further TBI data are only conducted in five states
- Many states call those on the registry within a month or two of a TBI incident report to provide resources and educational material

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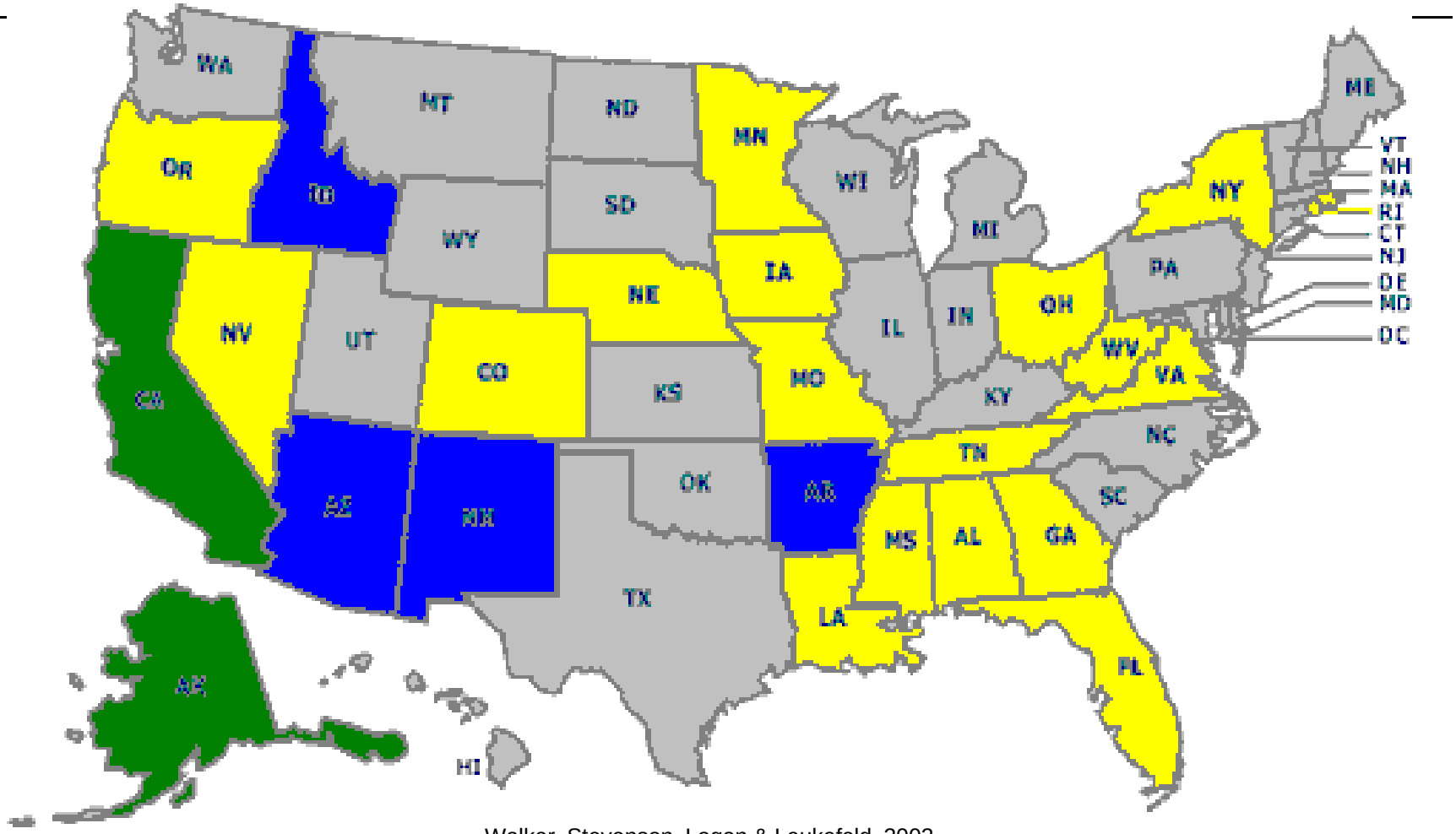
TBI Registries in 40% of States

Mandatory Voluntary Coming Soon No Registry



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General Trauma Registries

- Trauma registries collect information about all types of traumatic injuries – not just TBI or ABI
- They provide demographic, medical care and services, and cost of services information for a state
- Data are collected from hospitals, medical records, and trauma/ER departments

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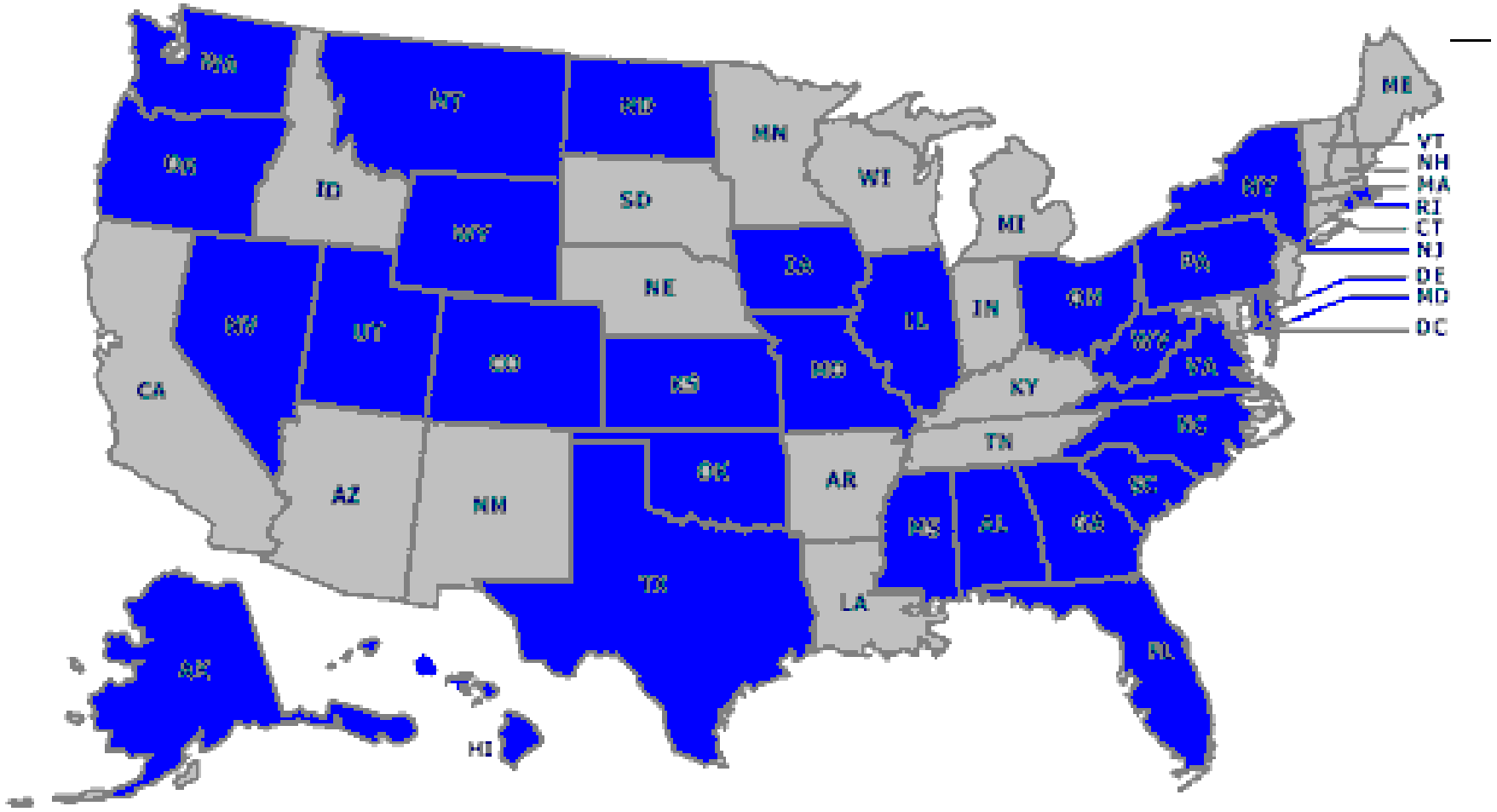
General Trauma Registries in 60% of States



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TBI Model Systems

- Created in 1987 through federal grant from Dept. of Education and National Institute on Disability Rehabilitation and Research
- Allow annual follow-ups and research with TBI patients and families at Model System Clinics
- Answer questions 1) Who sustains BI? 2) What are causes of BI? 3) What treatments are used and how much do they cost? and 4) What are the short and long-term outcomes?
- Based at Kessler Medical Ctr. in New Jersey
- www.tbindc.org

TBI Model System Sites

- Alabama – University of Alabama, Spain Rehab Center
- California – Rehab Research Center at Santa Clara Valley
- Colorado - Craig Hospital's Rocky Mt. Regional
- Massachusetts – Spaulding Rehab Hospital
- Michigan – Southeastern Michigan Rehab Institute
- Minnesota – Mayo Medical Center
- Mississippi – Methodist Rehab Center
- New Jersey – JFK-Johnson Rehab Center
- New York – Mt. Sinai School of Medicine
- North Carolina – Charlotte Institute of Rehab
- Ohio – Ohio State University
- Pennsylvania – Moss Rehab and University of Pittsburgh
- Texas – UT Southwestern Medical Center
- Virginia – Medical College of Virginia
- Washington – University of Washington

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Further Info from CDC

- Awaiting updated registry information from CDC due out in October that will give updated information about existing TBI registries

Why Do a Household Survey?

- ***Incidence data*** are, by definition, limited to new brain injury events
- To date, there has been no lifetime prevalence study, only estimates based on incidence data
- Prevalence studies of ***incidents*** in the past 6 months and past 12 months have been conducted
- To develop estimates of long-term service need and the at risk population of services, lifetime prevalence data are needed

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Lifetime Prevalence Head Injury Survey

- In 2002, the TBI Trust Fund Board allocated $40,000 to conduct a household survey as part of its plan to develop estimates of the number of persons in the state population who need brain injury related services
- The study began in November 2002 and ended in May 2003
- Using a telephone survey approach, the goal was to collect data from a large sample to have reliable results

INSTRUMENTATION

- The survey items were developed by the University of Kentucky Center on Drug and Alcohol Research based on the literature and the survey was reviewed by the Department of Mental Health-Mental Retardation Brain Injury Services Unit
- Telephone interviewers were trained on the instrument and were supplied with probes to improve participant understanding

SAMPLE QUESTIONS

1. How was this person injured?

2. Did this person's injury result from his or her:
(Check all that apply)

a) Not using a safety helmet
b) Not using a safety belt
c) Speeding or other risky driving
d) None of the above

3. Did this person lose consciousness or enter a coma, as a result of the head injury?

4. Did the injured person go to an emergency room following the injury?

5. Was the injured person kept in a hospital for at least one night?

6. Did the injury result in changes in the person's behavior in any of the following ways?

(Check all that apply)

a) increased depression
b) increased anxiety
c) changed personality traits
d) increased drug or alcohol use
e) memory problems

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DRAFT FINDINGS

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- 3,267 households were contacted out of 8,719 potential households in the RDD sample
- The overall response rate was 37.5%, with a 35% refusal rate
- 27.5% of the attempts were to numbers that had various other problems including constant busy signals, call blocking or answering machines

DRAFT FINDINGS

- The regional distribution of calls and contacts was proportionate to all mental health planning regions of the state with one exception – Bluegrass was over represented in responses
- Data were collected by county of residence of the respondent and all counties were included in the study, but county level data are too small for representation

Households Contacted by Mental Health Region Compared with Regional Population (n=3267)

Mental Health Region	Number Contacted	Percent	2000 Census Regional Population	Percent of Total State Population
1 Four Rivers – Paducah	174	5.3	203,299	5.0
2 Pennyroyal – Hopkinsville	158	4.8	205,715	5.1
3 Valley – Owensboro	185	5.7	207,377	5.1
4 Lifeskills – Bowling Green	190	5.8	255,225	6.3
5 Communicare - Elizabethtown	197	6.0	243,202	6.0
6 Seven Counties – Louisville	664	20.3	869,306	21.5
7 NorthKY – Covington	283	8.7	391,417	9.7
8 Comprehend - Maysville	37	1.1	55,229	1.4
10 Pathways – Ashland	178	5.4	212,086	5.2
11 Mountain – Prestonsburg	101	3.1	160,532	4.0
12 Kentucky River – Jackson	97	3.0	120,656	3.0
13 Cumberland River – Corbin	215	6.6	238,270	5.9
14 Adanta – Somerset	177	5.4	193,452	4.9
15 Bluegrass - Lexington	611	18.7**	686,003	17.0
Total	3267	100.0	4,041,769	100.0

***p <.01*

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Regional Distribution of Households with a Person with a Brain Injury (n=633)

Mental Health Region	Households with Injured Persons	Percent of Total	2000 Census Regional Population	Percent of Total State Population
1 Four Rivers - Paducah	29	4.6	203,299	5.0
2 Pennyroyal - Hopkinsville	21	3.3	205,715	5.1
3 Valley - Owensboro	39	6.2	207,377	5.1
4 Lifeskills - Bowling Green	23	3.6**	255,225	6.3
5 Communicare - Elizabethtown	51	8.1	243,202	6.0
6 Seven Counties - Louisville	132	20.9	869,306	21.5
7 Northkey - Covington	53	8.4	391,417	9.7
8 Comprehend - Maysville	9	1.4	55,229	1.4
10 Pathways - Ashland	33	5.2	212,086	5.2
11 Mountain - Prestonsburg	19	3.0	160,532	4.0
12 Kentucky River - Jackson	25	3.9	120,652	3.0
13 Cumberland Valley - Corbin	49	7.7	382,706	5.9
14 Adanta - Somerset	37	5.8	193,452	4.9
15 Bluegrass - Lexington	113	17.9	686,003	17.0
Total	633	100	4,041,769	100.1[a]

***p <.01*

[a] Sum over 100% due to rounding.

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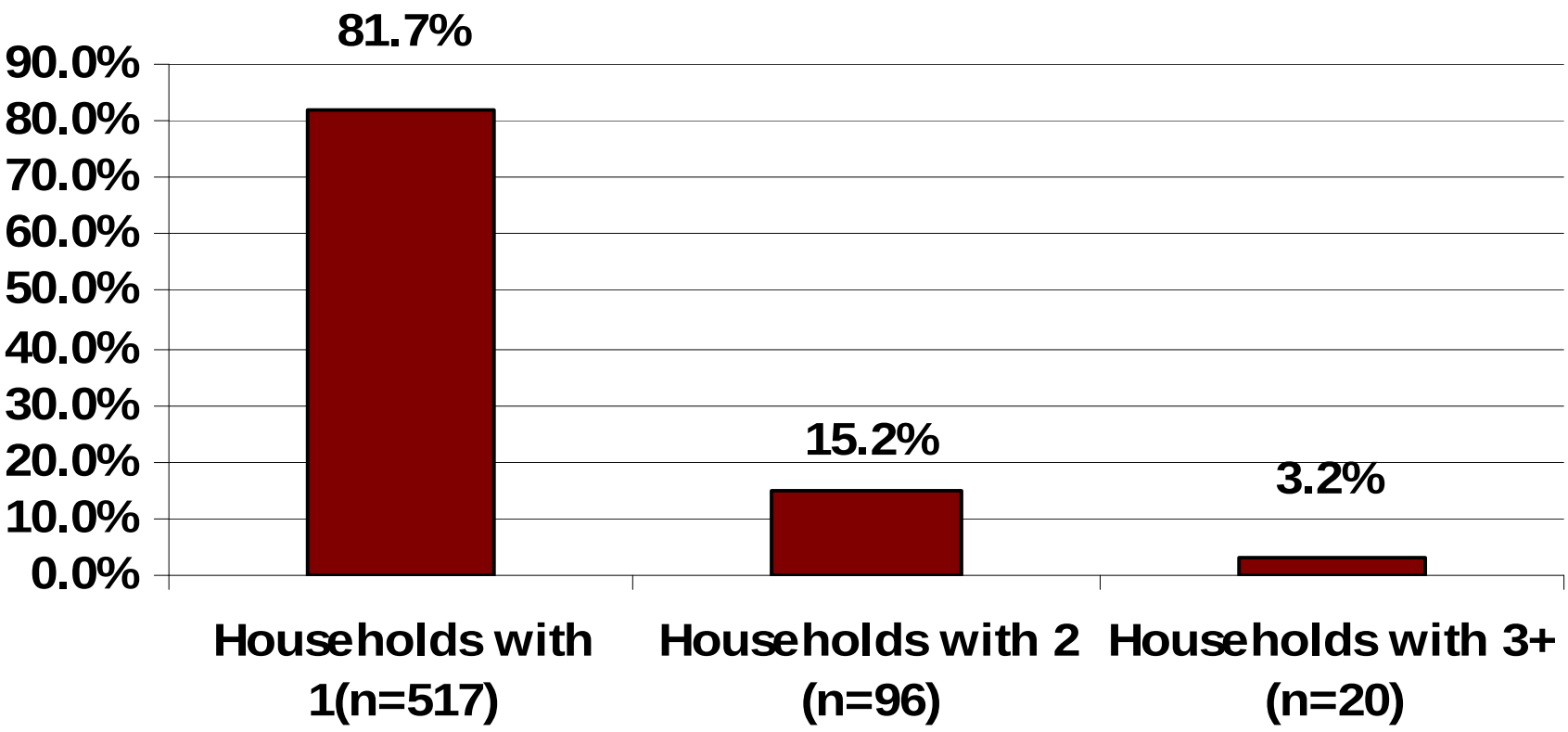
Households with 1, 2, or 3+ Persons with Head Injuries
(n=633)



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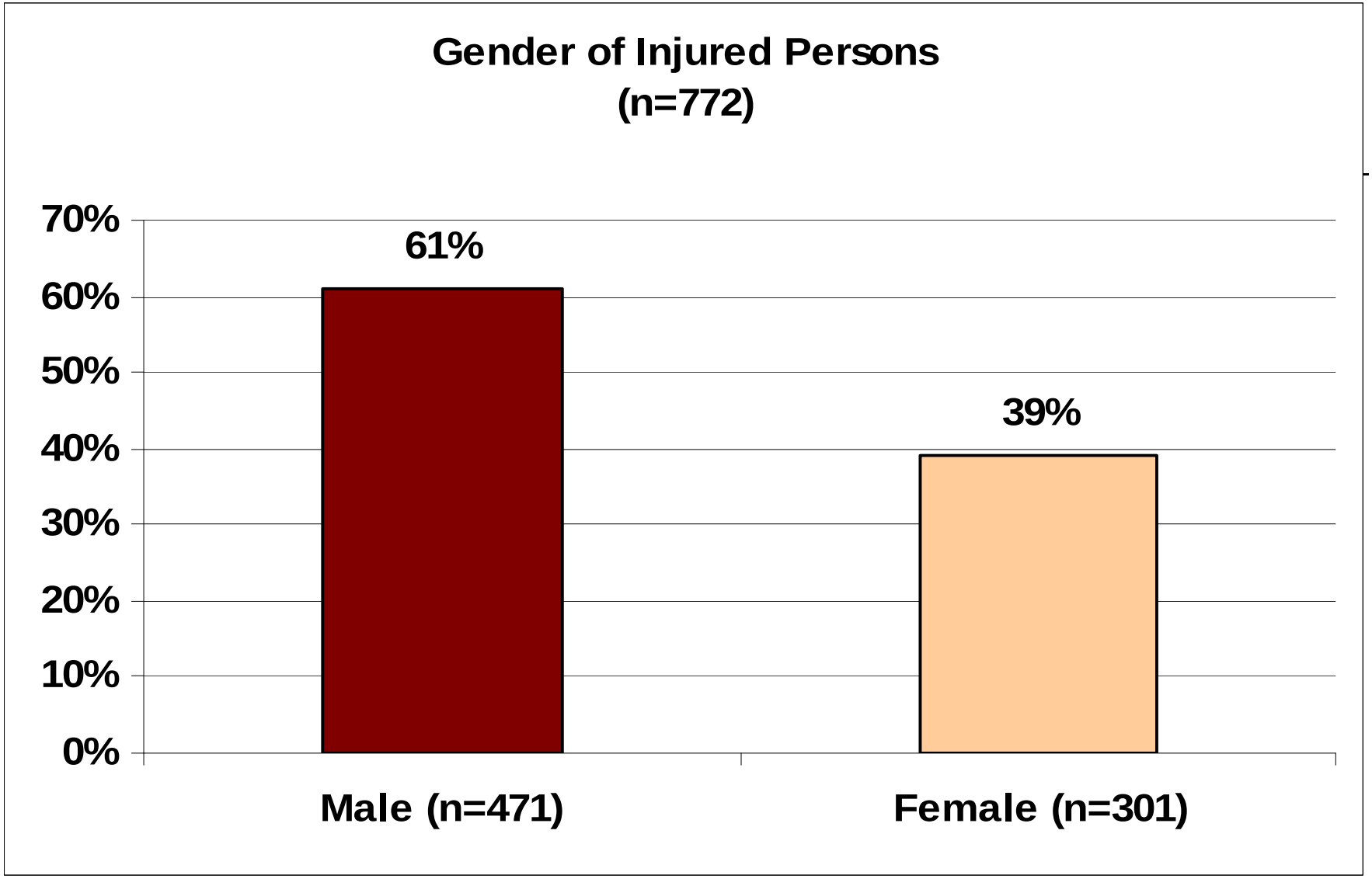

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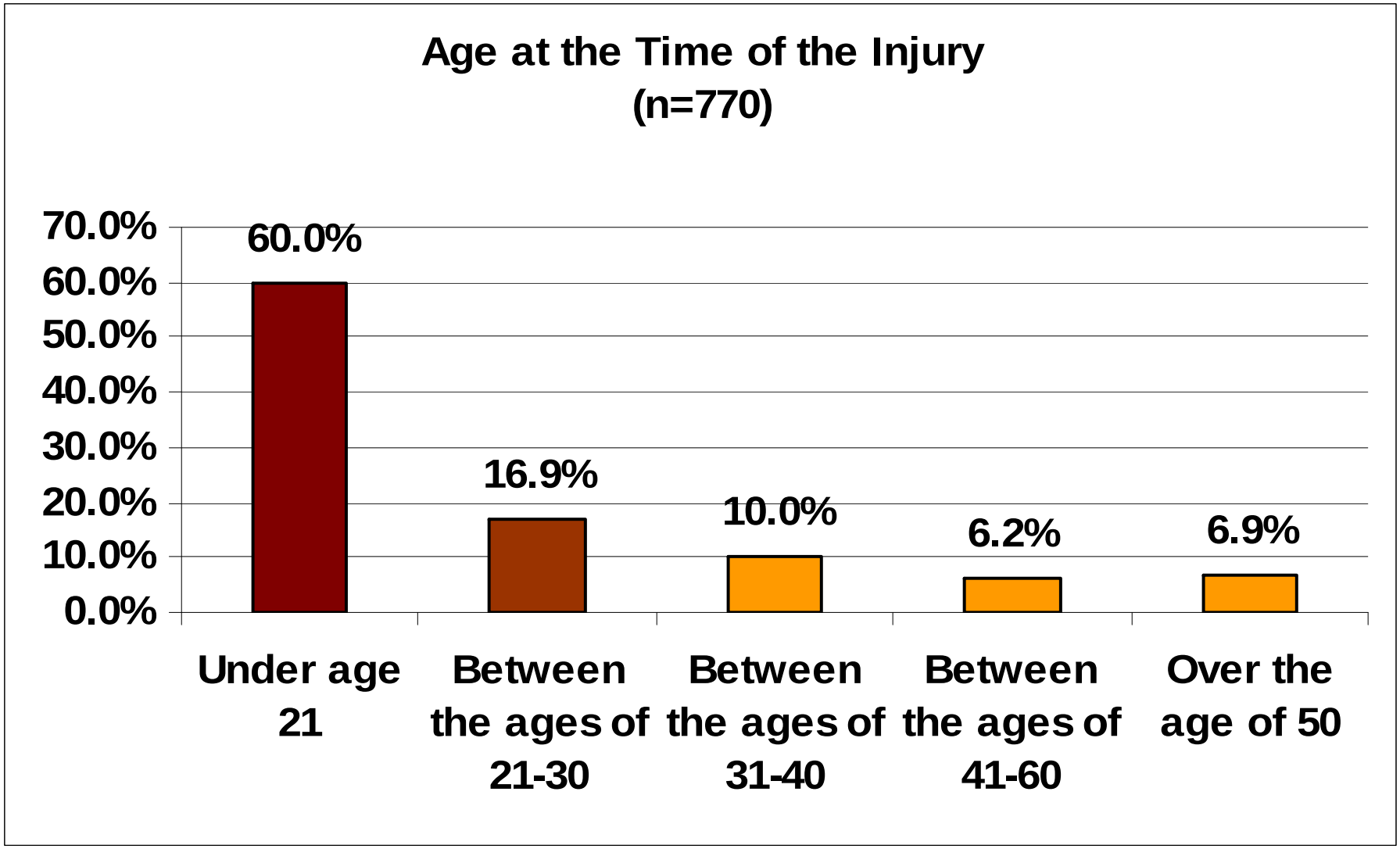

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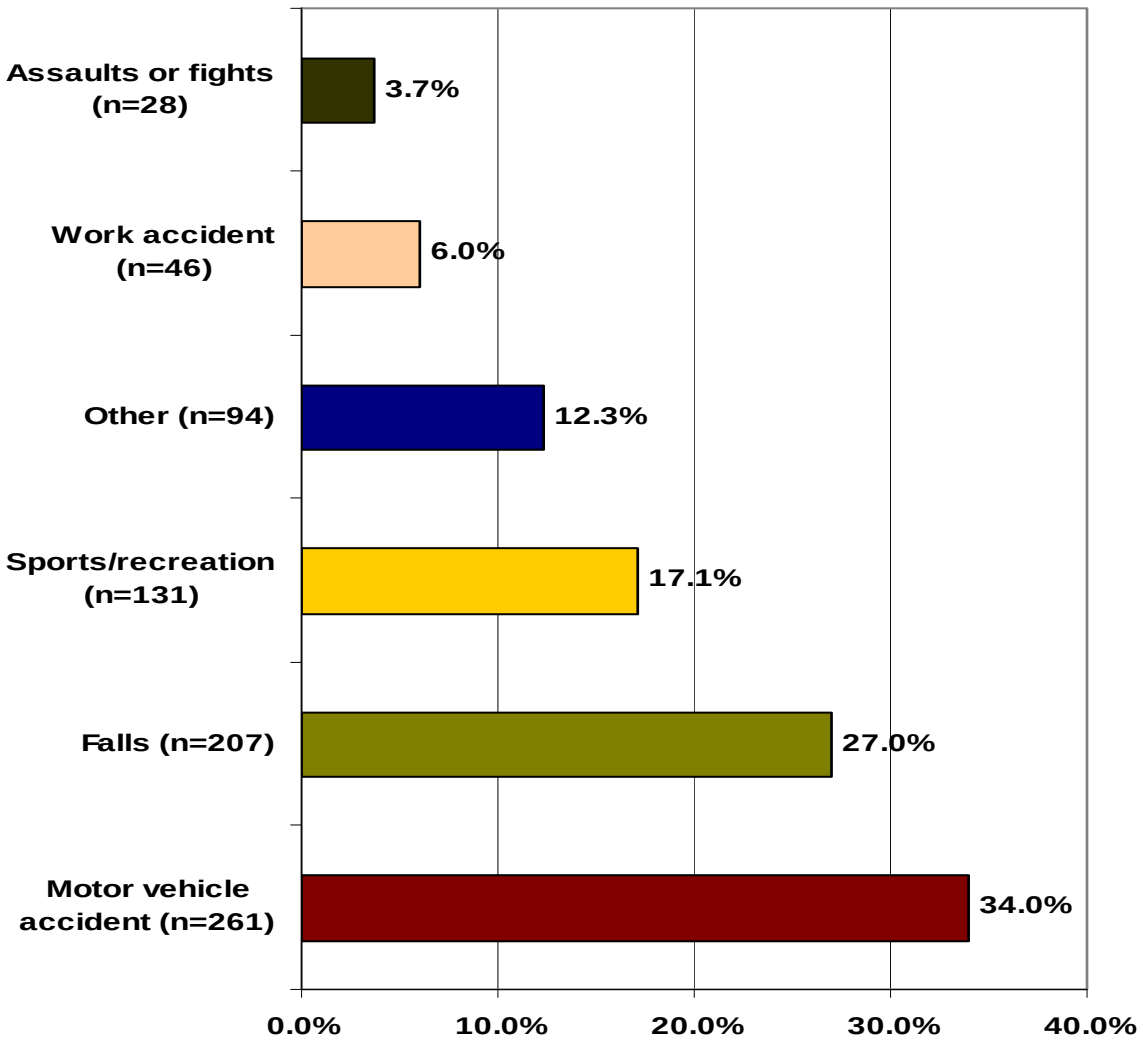
Sources of Injuries (n=767)



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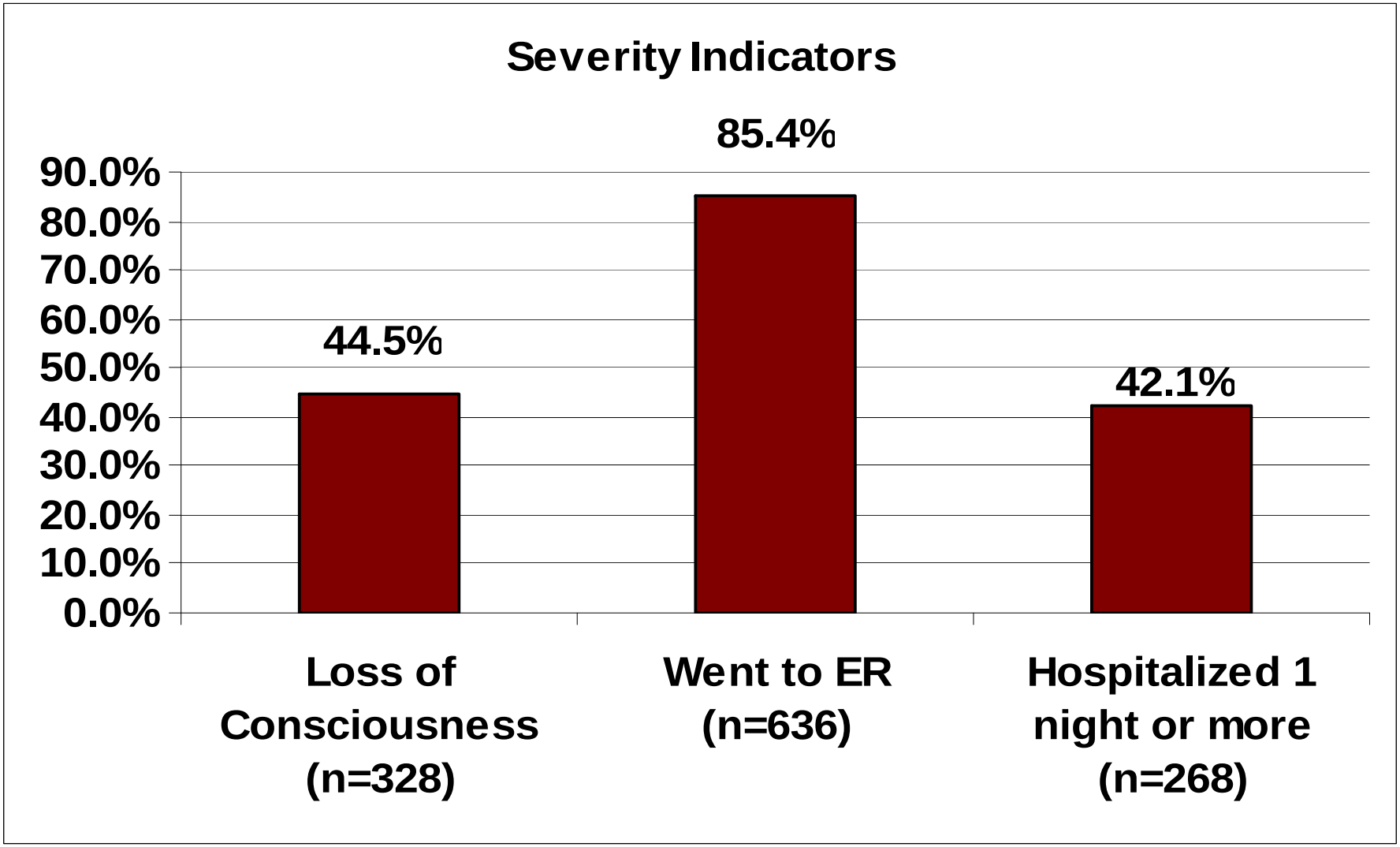

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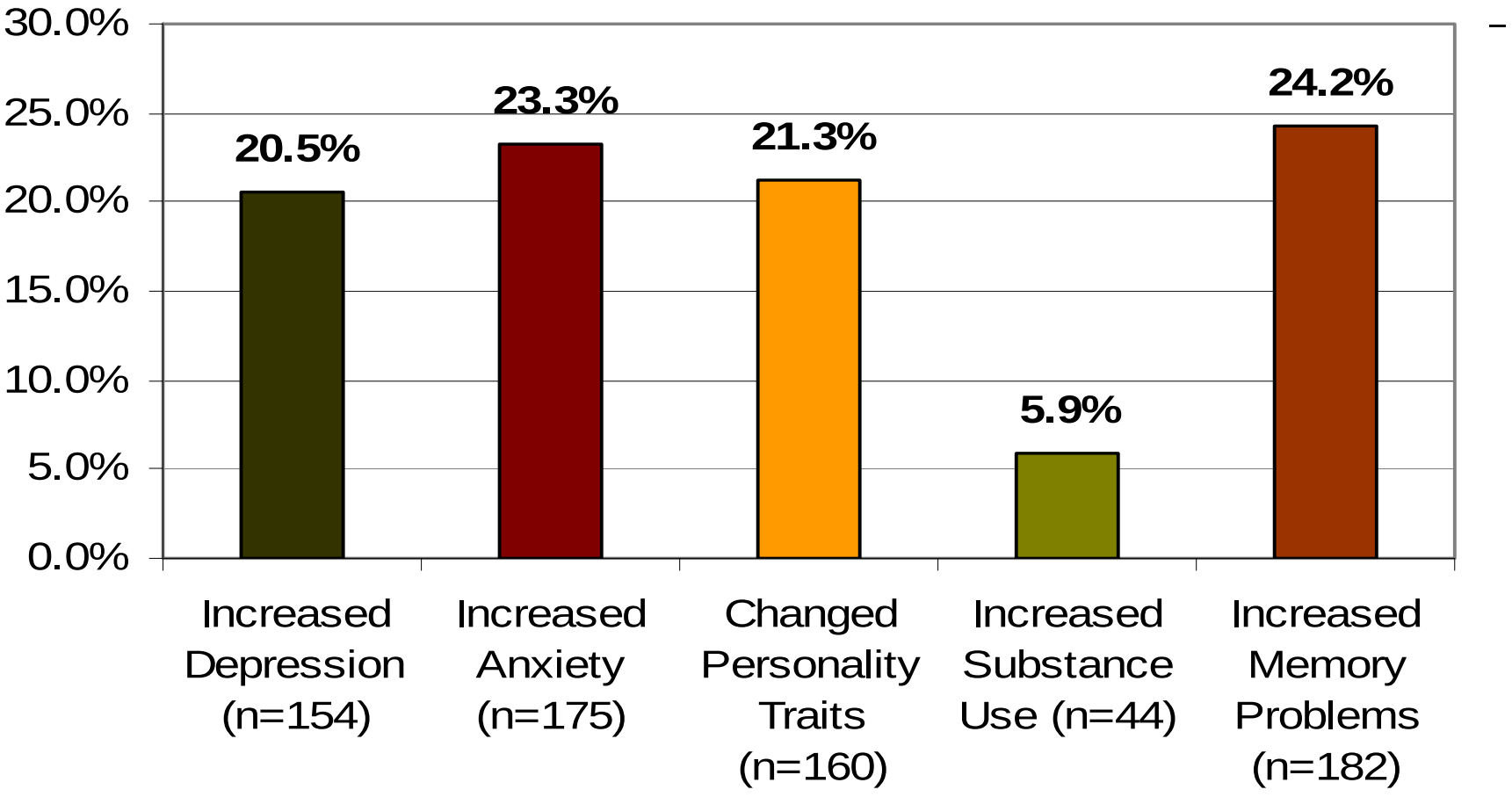
Severity Indicators



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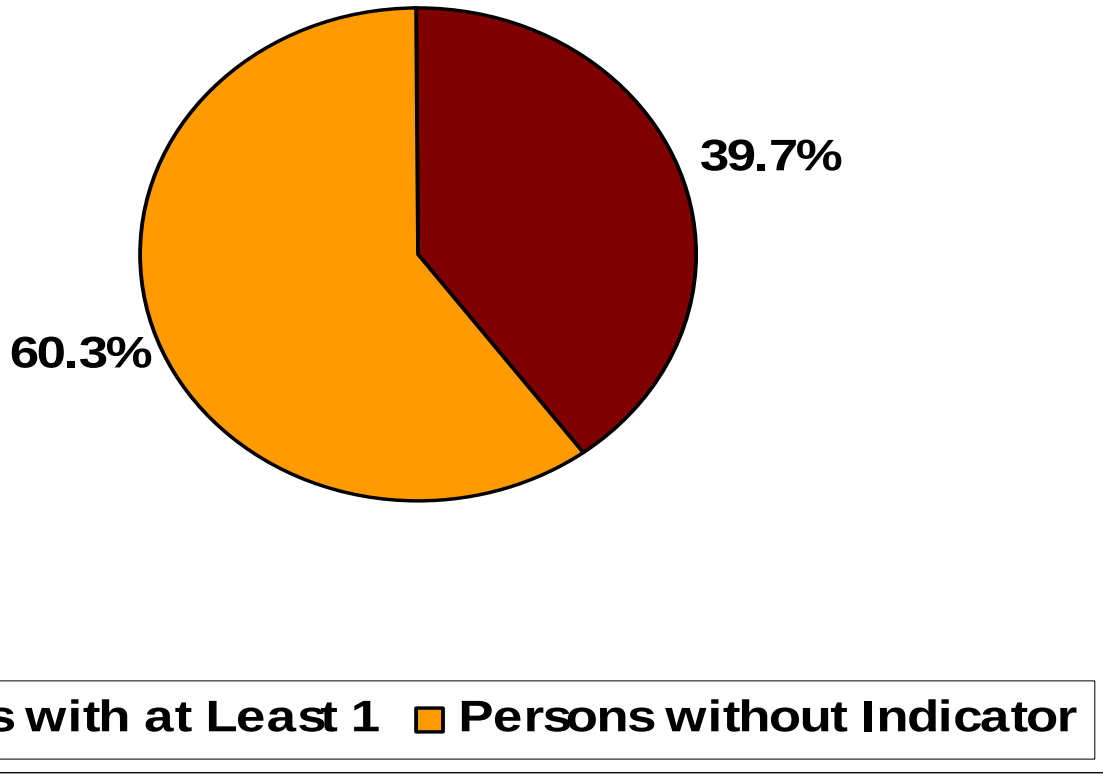
Persons with Any Severity Indicator (n=751)



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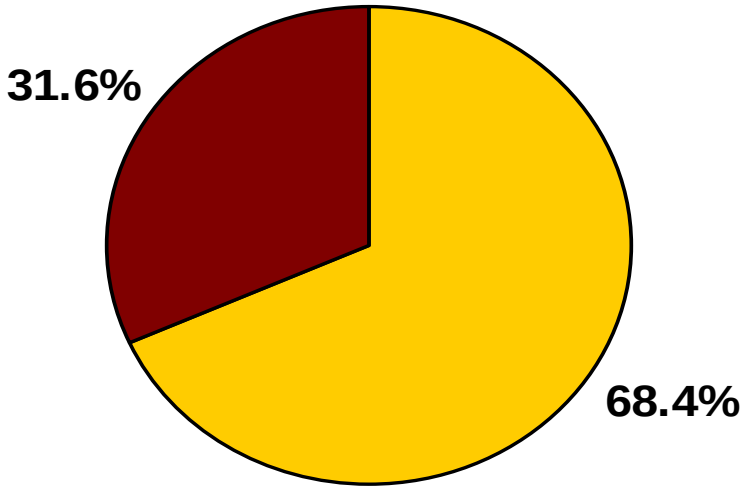
Persons with HI Who Used Services (n=744)



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TYPES OF SERVICES USED (n=235)

Type of Professional Services Used	Percent of Persons Using Services
Mental health services (n=70)	29.8
Specialized equipment (n=61)	26.0
Physical Therapy, Speech, or Occupational Therapy (n=95)	40.4
Vocational training (n=26)	11.1
Substance abuse counseling (n=12)	5.1
Personal care assistance (n=53)	22.6
Environmental modifications (n=31)	13.2
Residential Treatment or Rehabilitation (n=51)	21.7
Other medical services (n=86)	36.6

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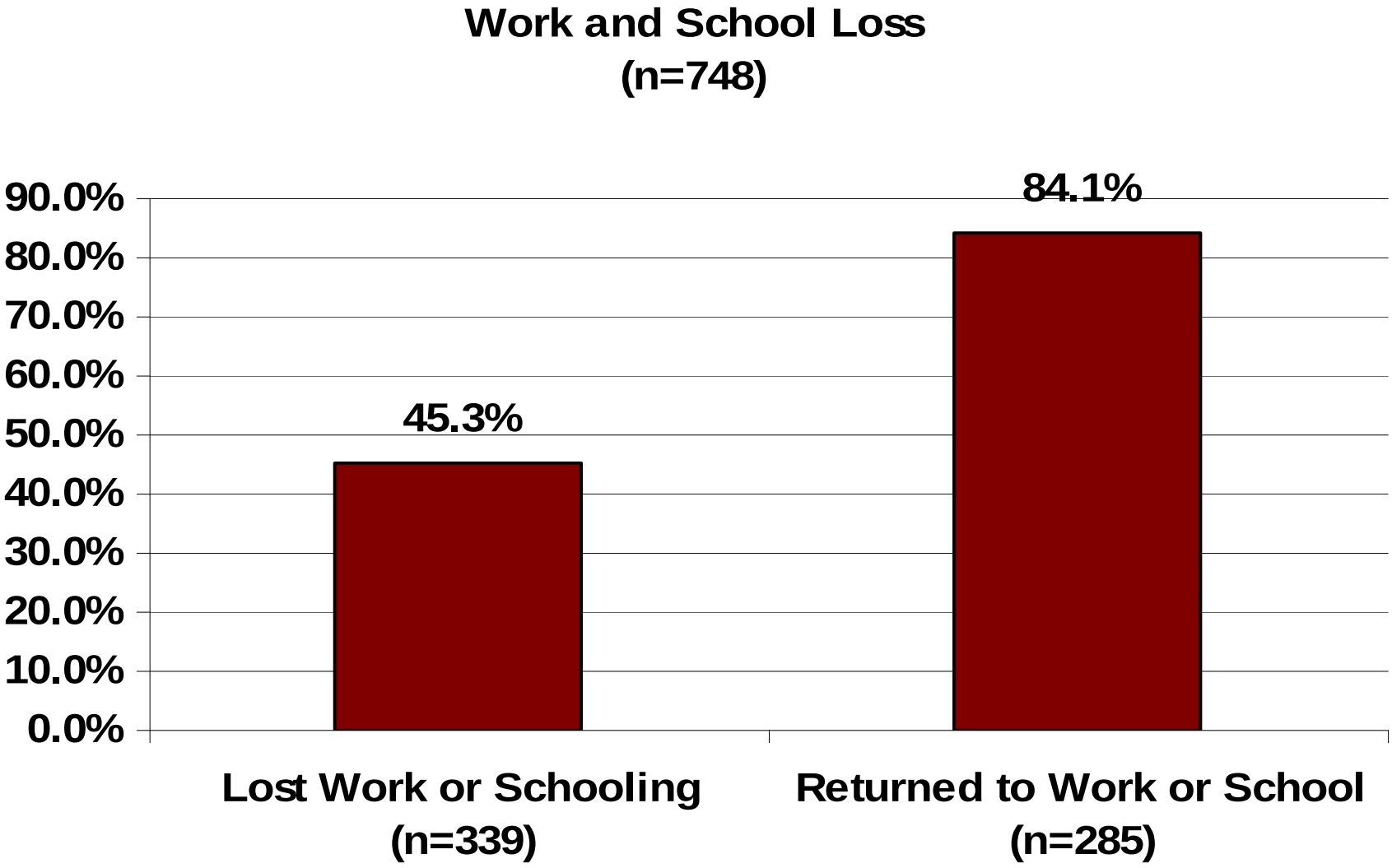

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SUMMARY OF FINDINGS

- The margin of error for the sample of 3,267 households is ±1.71% at the 95% confidence level
- Findings suggest that 19.4% of households in Kentucky have at least one member with a history of a head injury
- These data suggest that there are 308,586 households with at least one member with a head injury history
- Selected severity measures for consequences of head injuries suggest that 39.7% of injured persons have at least one psychological or medical indicator of head injury sequelae
- These data suggest that all regions but one have a rate of head injury proportionate to population size

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SUMMARY OF FINDINGS

- The average household size for this sample was 1.93 persons, thus the study includes an estimated 6,305 persons among the 3,267 households from whom data were collected
- 772 injured persons were identified among the 3,267 households
- The 772 persons represent 12.2% of the sample, suggesting that 493,096 persons in Kentucky might report a lifetime exposure to head injury
- Using severity indicators, this would suggest a crude prevalence estimate of 4.8% of the state population, or over 190,000 Kentuckians, with head injuries with potentially clinically significant problems that could require continued services in the future

LIMITATIONS

- This study used a random-digit-telephone dialing program to contact household members and 4.7% of Kentucky households do not have telephones (some regions have over 10% with no phone service)
- The sample may be biased due to telephone survey approach
- The survey was restricted to a narrow set of questions and did not use clinical criteria to assess brain injury among those who reported head injuries
- The survey was limited to one state in the southeastern part of the country

CONCLUSION

- This is the first lifetime prevalence study of head injury among the general population in the country
- Using epidemiological methods like those used in needs assessment surveys for mental health and substance abuse problems, the study examined the lifetime prevalence of head injury among 3,267 households in Kentucky
- These data suggest that Kentucky has a significant number of persons with a history of head injuries who may be at risk for health, mental health, rehabilitation, and other services in the future
- Future studies should examine head injuries and their sequelae in greater detail to better understand problems that may require continuing services