



CHILDHOOD CANCER IMPACT ON THE FAMILY

SIOP/ICCCPO MEETING
OCTOBER 28, AUCKLAND NZ

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ACCO SURVEY

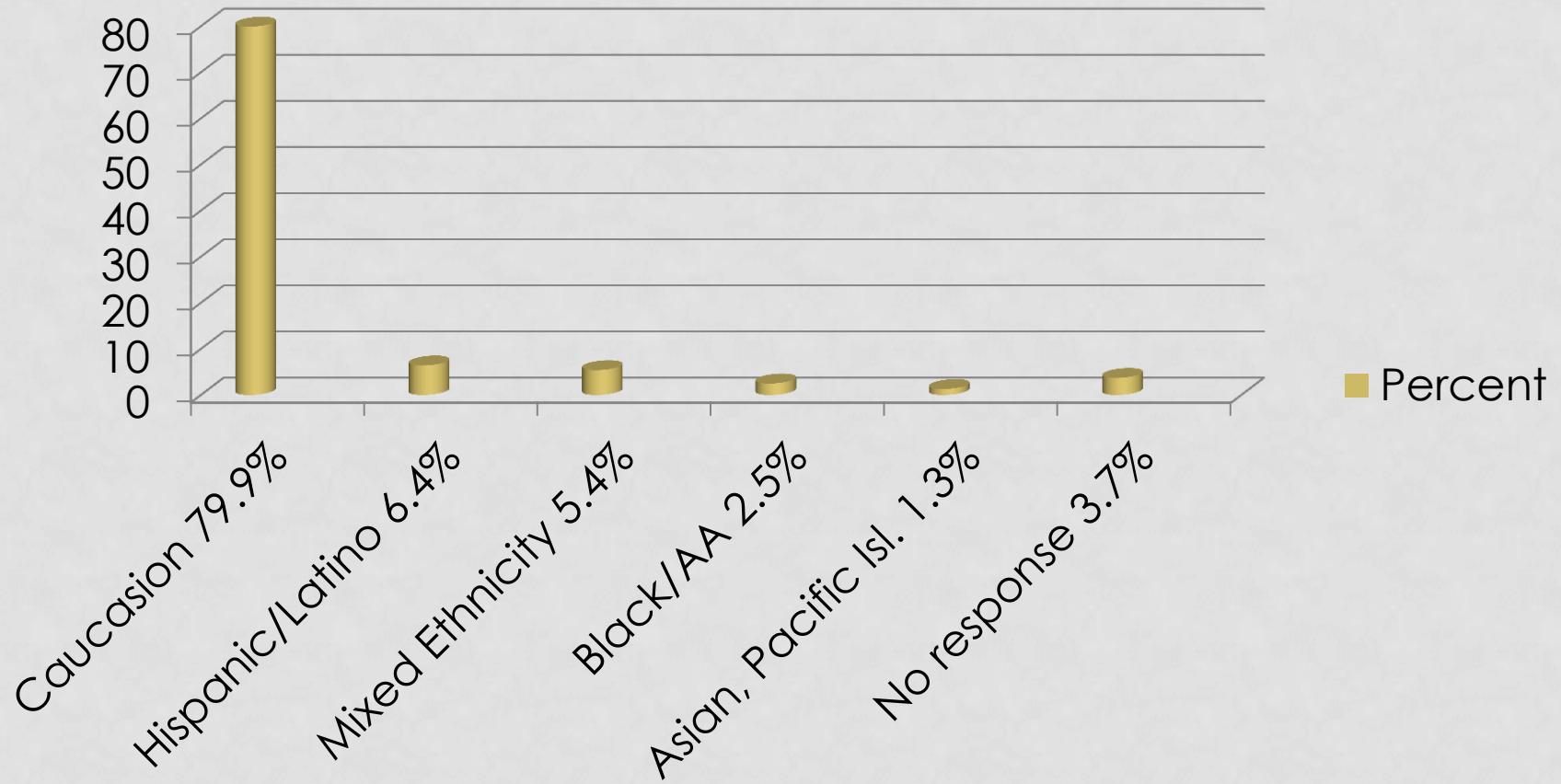
990 RESPONSES

Respondents:

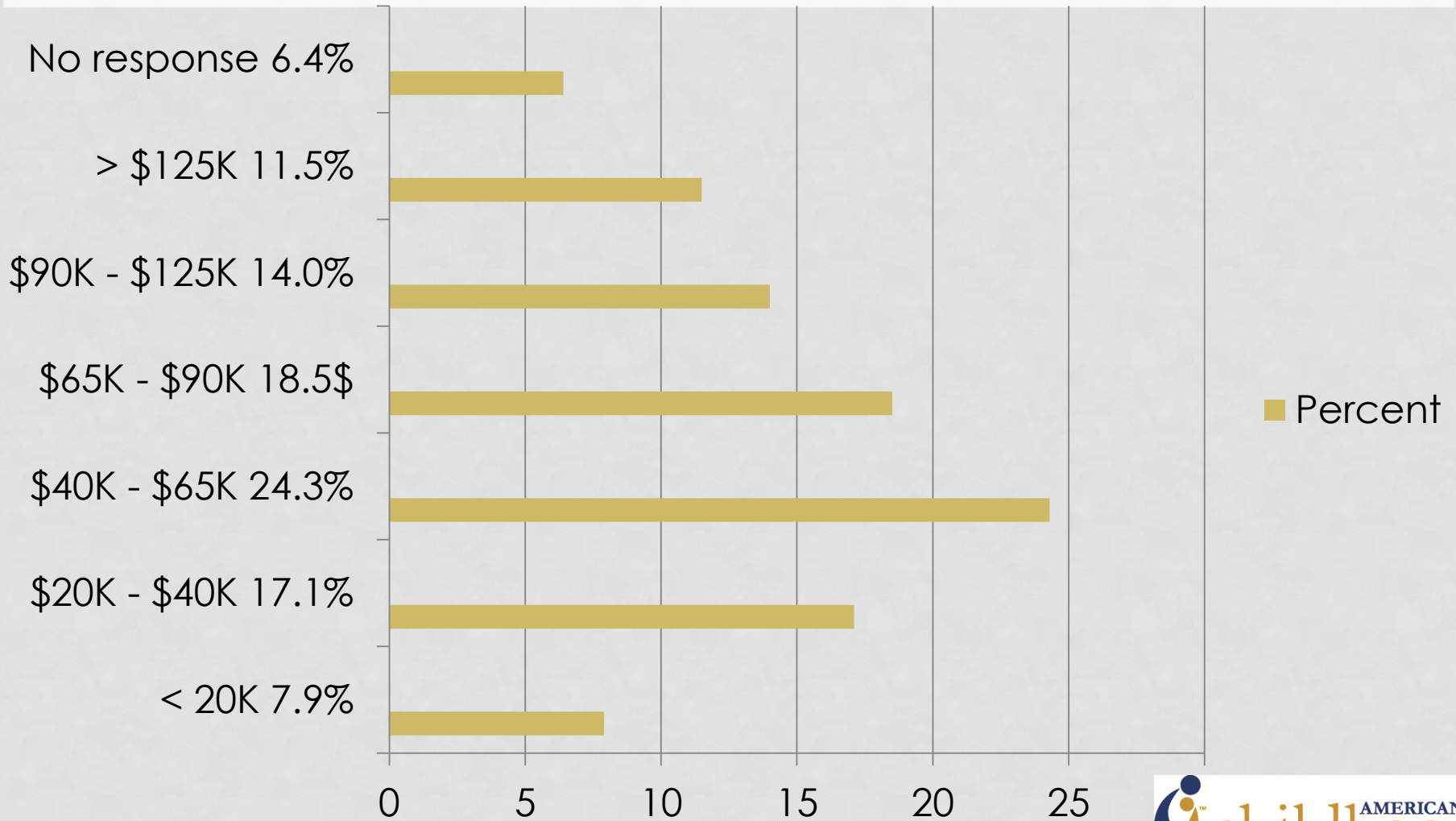
- 79.1% biological mother of the child/adolescent diagnosed with cancer
- 6.8 biological father of the child/adolescent diagnosed with cancer
- 2.6% Survivor
- 5% Grandparent or legal guardian
- 5% other (adoptive parent, other relative)

DEMOGRAPHICS

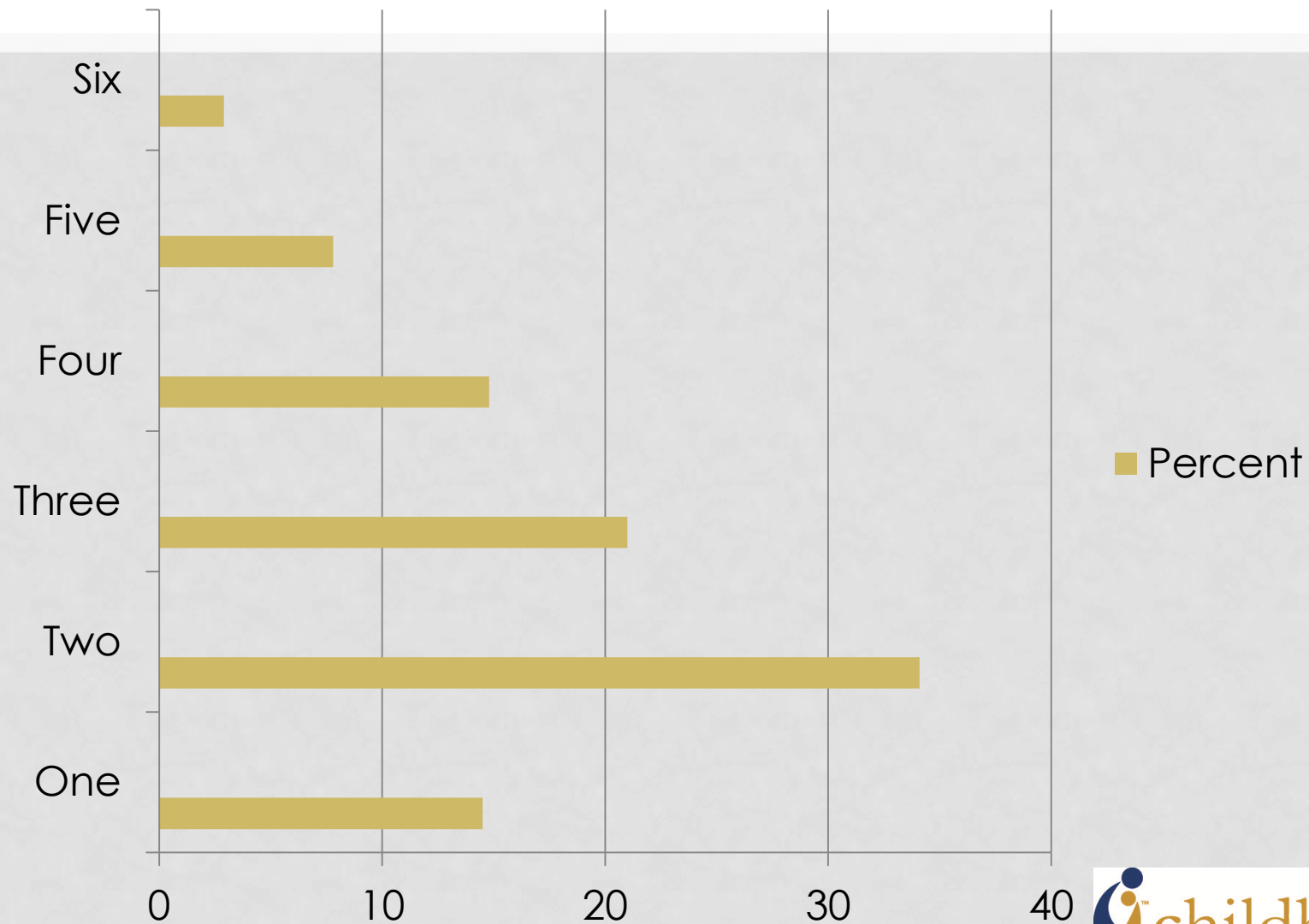
ETHNICITY



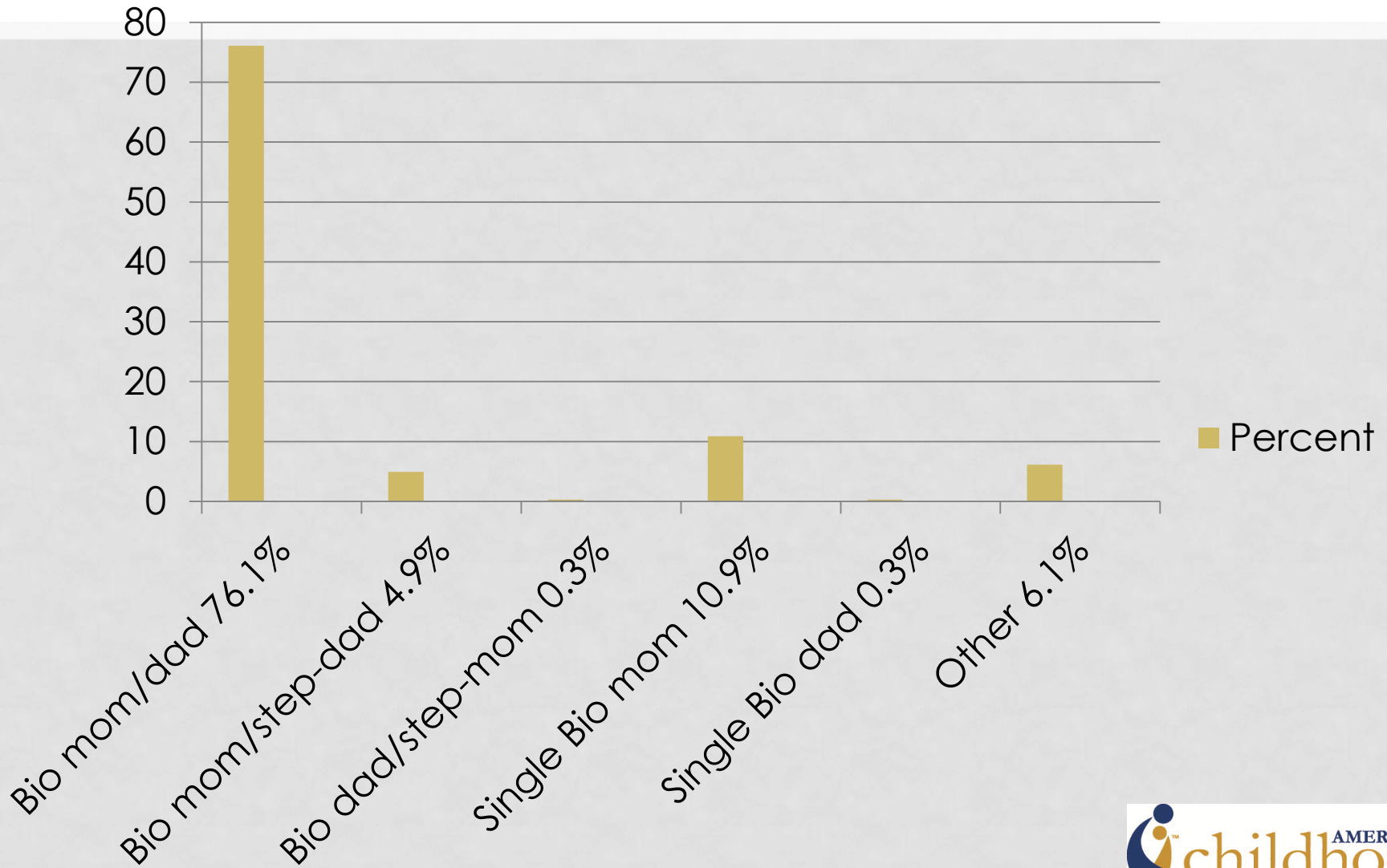
ANNUAL FAMILY INCOME



HOUSEHOLD DEPENDENTS



HOUSEHOLD MAKEUP



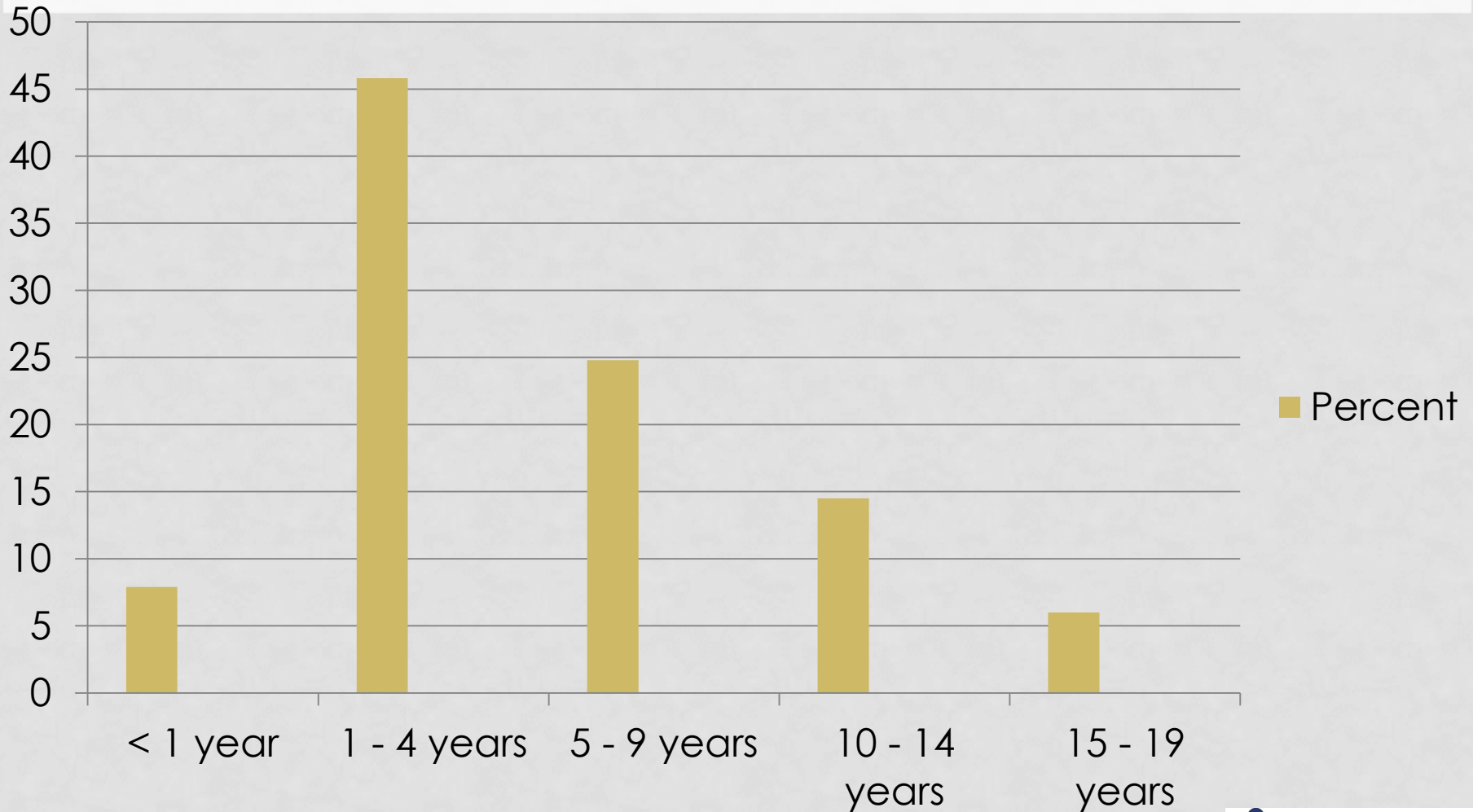
NUMBER CHILDREN IN FAMILY DIAGNOSED

- 94.7% one child
- 1.3% two children
- Other (deceased, survivor taking survey)

OTHER FAMILY MEMBERS DIAGNOSED WITH CANCER

- 3.9% Biological mother
- 2.7% Biological father
- 0% Step-mother or step-father

AGE CHILD DIAGNOSED



DIAGNOSES

- ALL: 38%
- AML: 3.8%
- Brain: 23.3%
- Neuroblastoma: 8.6%
- Wilms: 5.1%
- Rhabdo: 4.4%
- Osteo: 3.3%
- NHL: 2.8%
- Ewings: 2.5%
- Hepatoblastoma: 2.1%
- Other: 6.1%

REFERRED TO ...

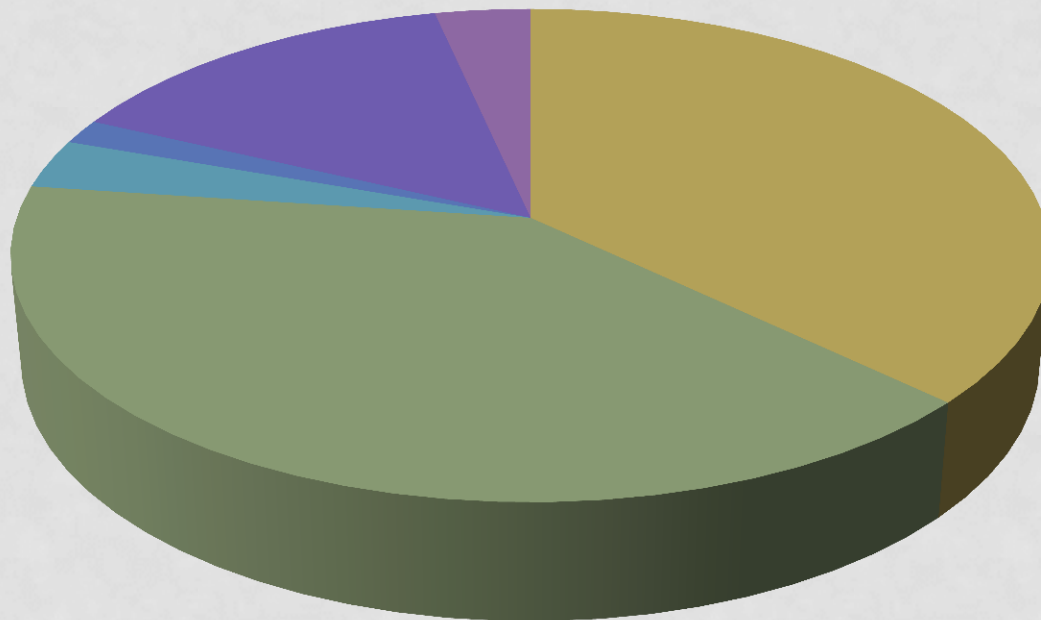
Other - VA, Non-teaching
13.4%

**Local Community
Hospital: 21%**

**Children's Teaching
Hospital 64.2%**

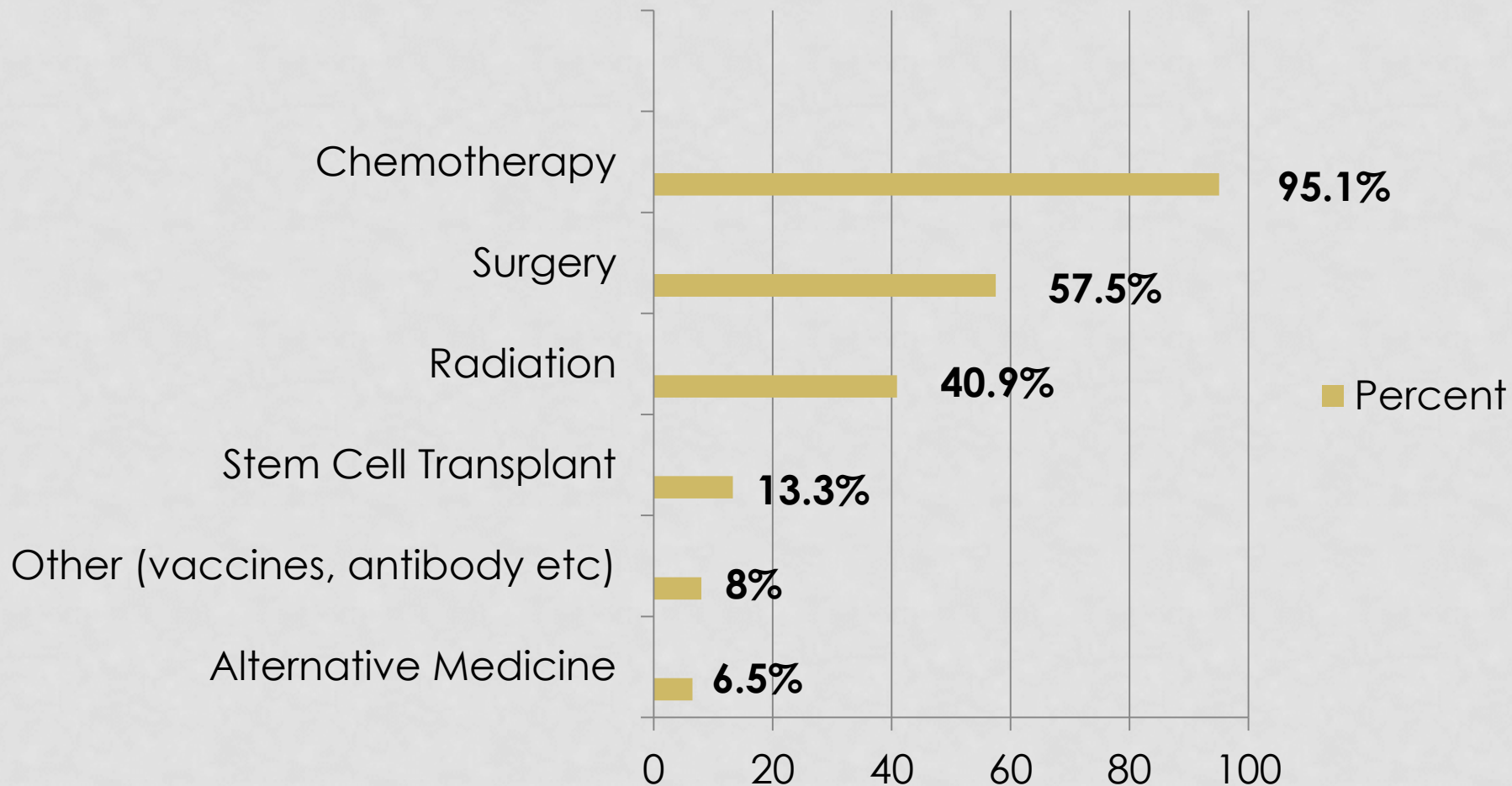
CURRENT STAGE OF TREATMENT

Percent



- On Treatment 36.6%
- Treatment Completed 39.6%
- Relapsed 3.2%
- Treatment Terminated 1.6%
- Deceased 14.4%
- Other 3.4%

TYPES OF TREATMENT



DURATION OF TREATMENT

- Range was 4 months to 10 years (3 occurrences)
- Average 2.5 to 3 years

TREATMENT DENIED OR RESCINDED

- **Yes: 15.5%**
- **No: 78.0%**

Reasons:

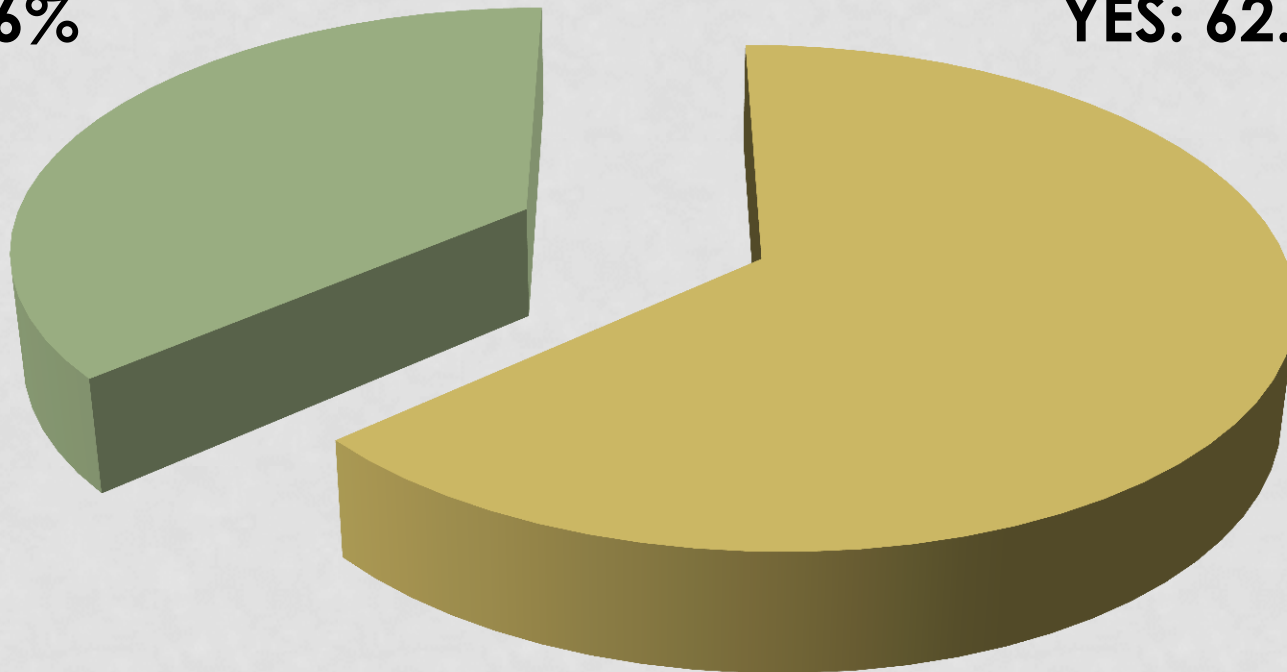
- Experimental Therapy (20.6%)
- Recommended by Doctor but not warranted by insurance (31.2%)
- Not covered under plan – example transplant (6.2%)
- Clinical Trial - only covers standard of care (8.7%)
- Capped insurance coverage (11.2%)
- Other (out of network, drug not FDA approved for pediatric use etc. 23.1%)

OFFERED TO PARTICIPATE IN CLINICAL TRIAL

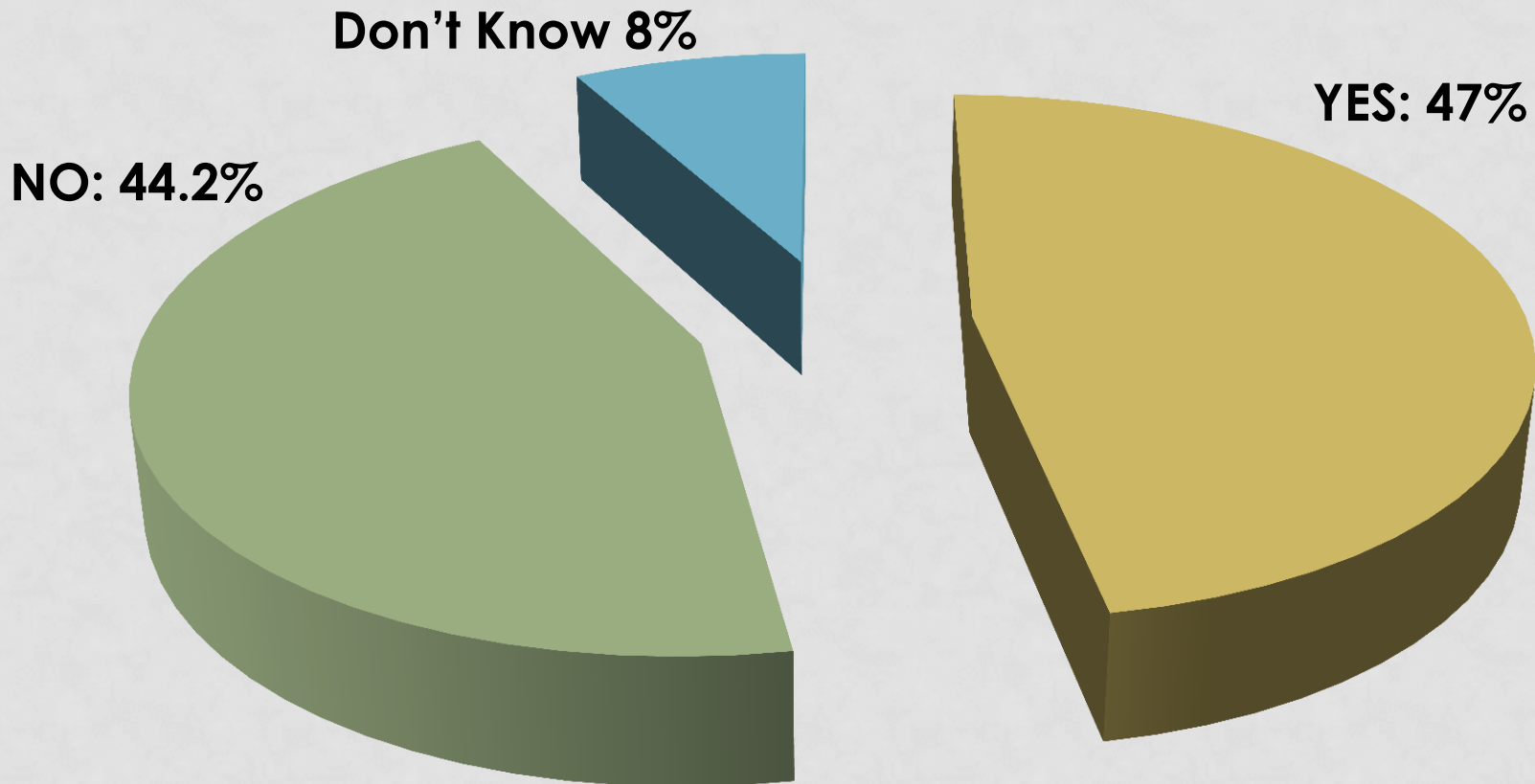
Percent

NO: 36%

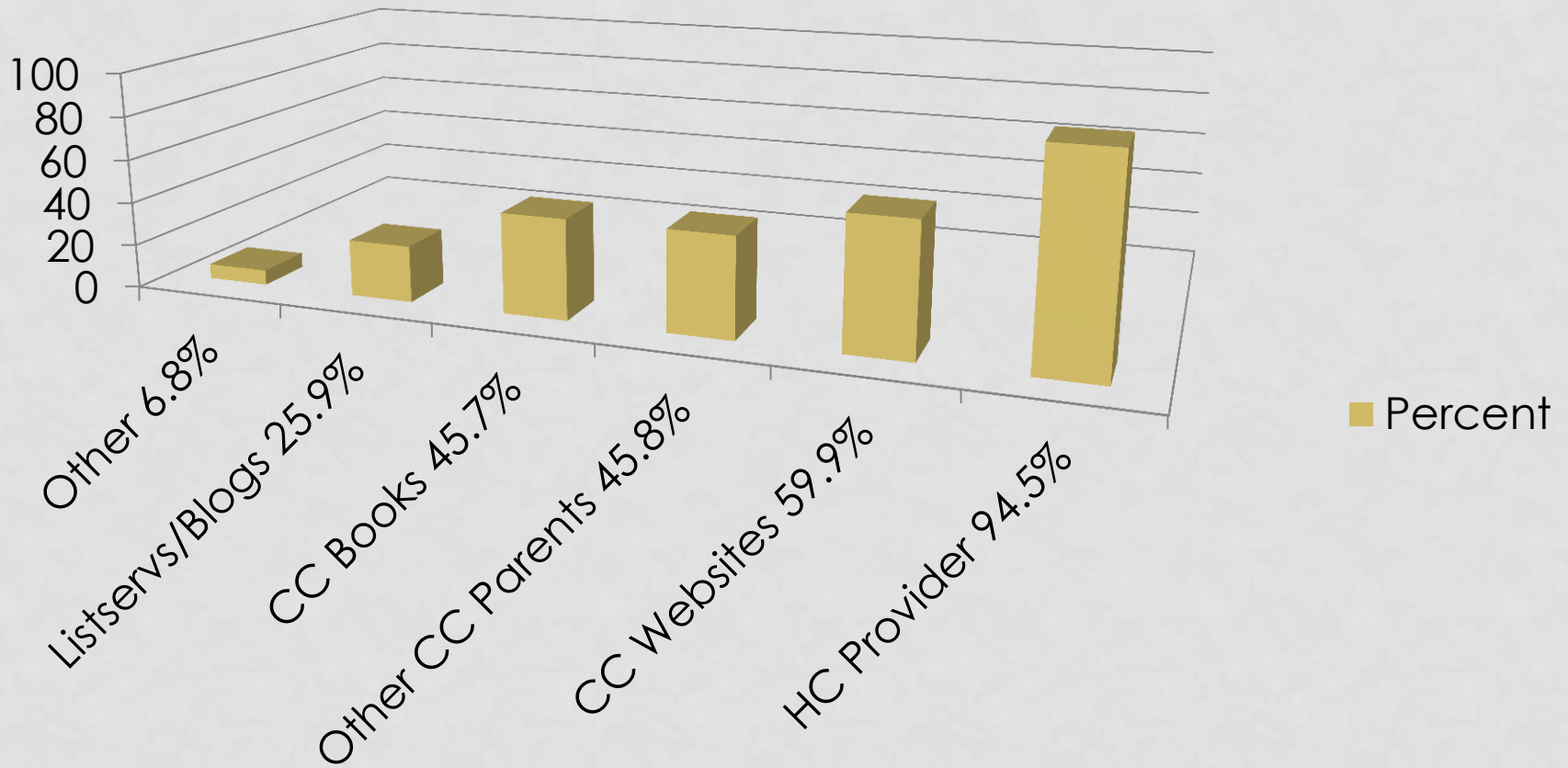
YES: 62.8%



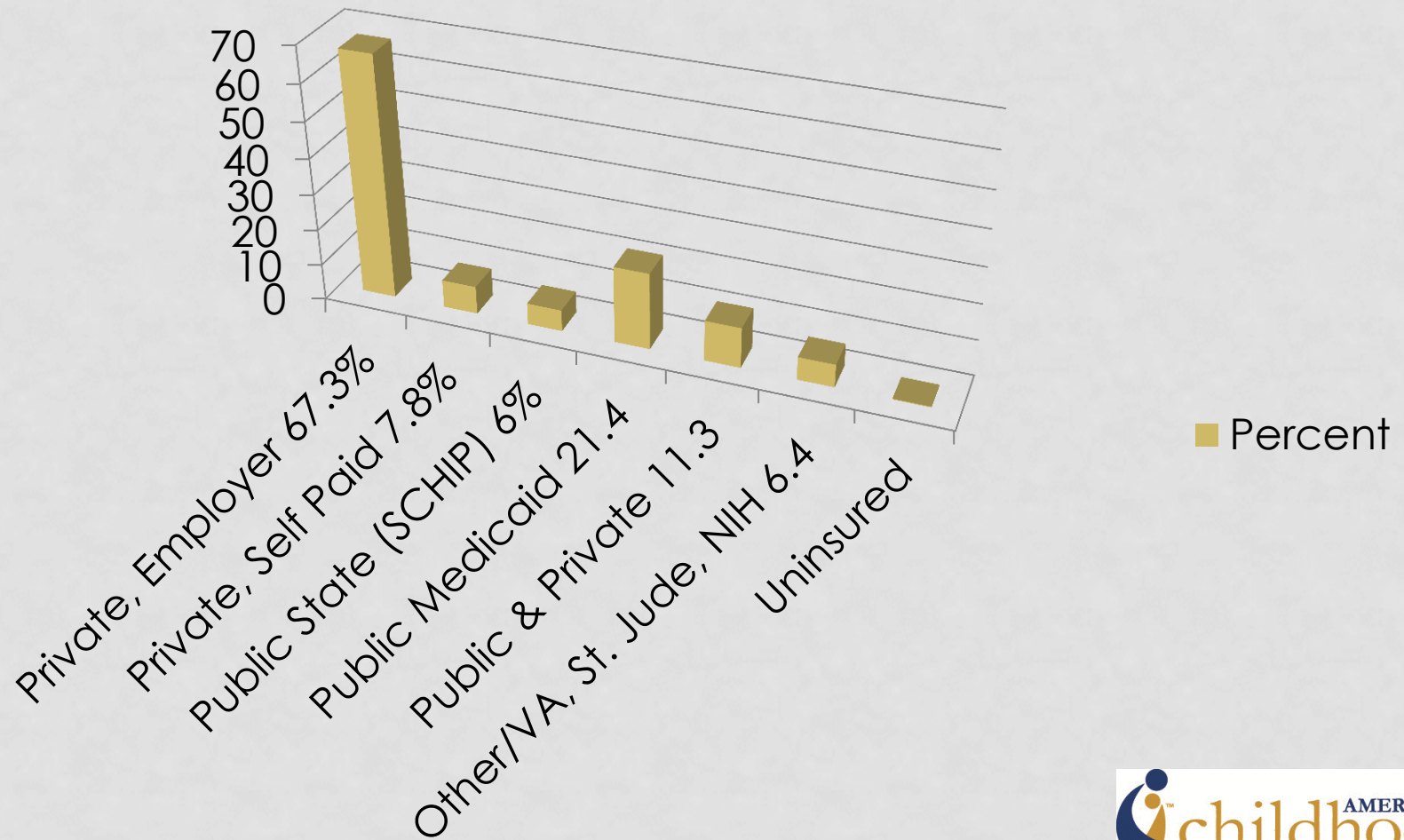
ENTERED INTO CLINICAL TRIAL



SOURCE OF INFORMATION FAMILIES TURNED TO

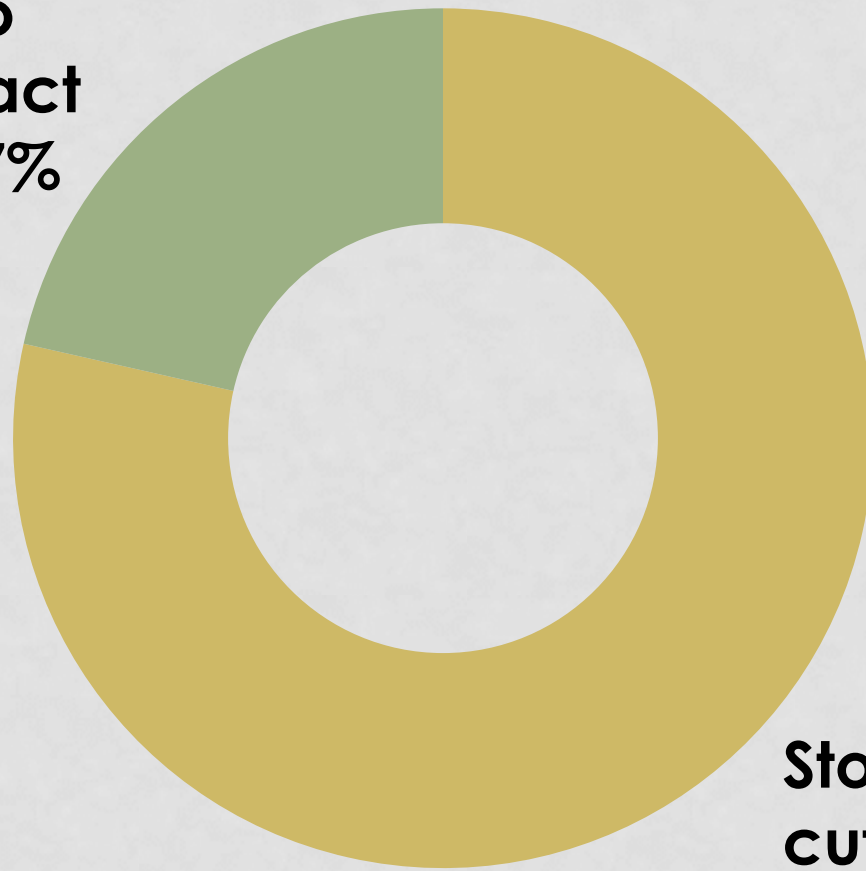


SOURCE OF HEALTHCARE COVERAGE



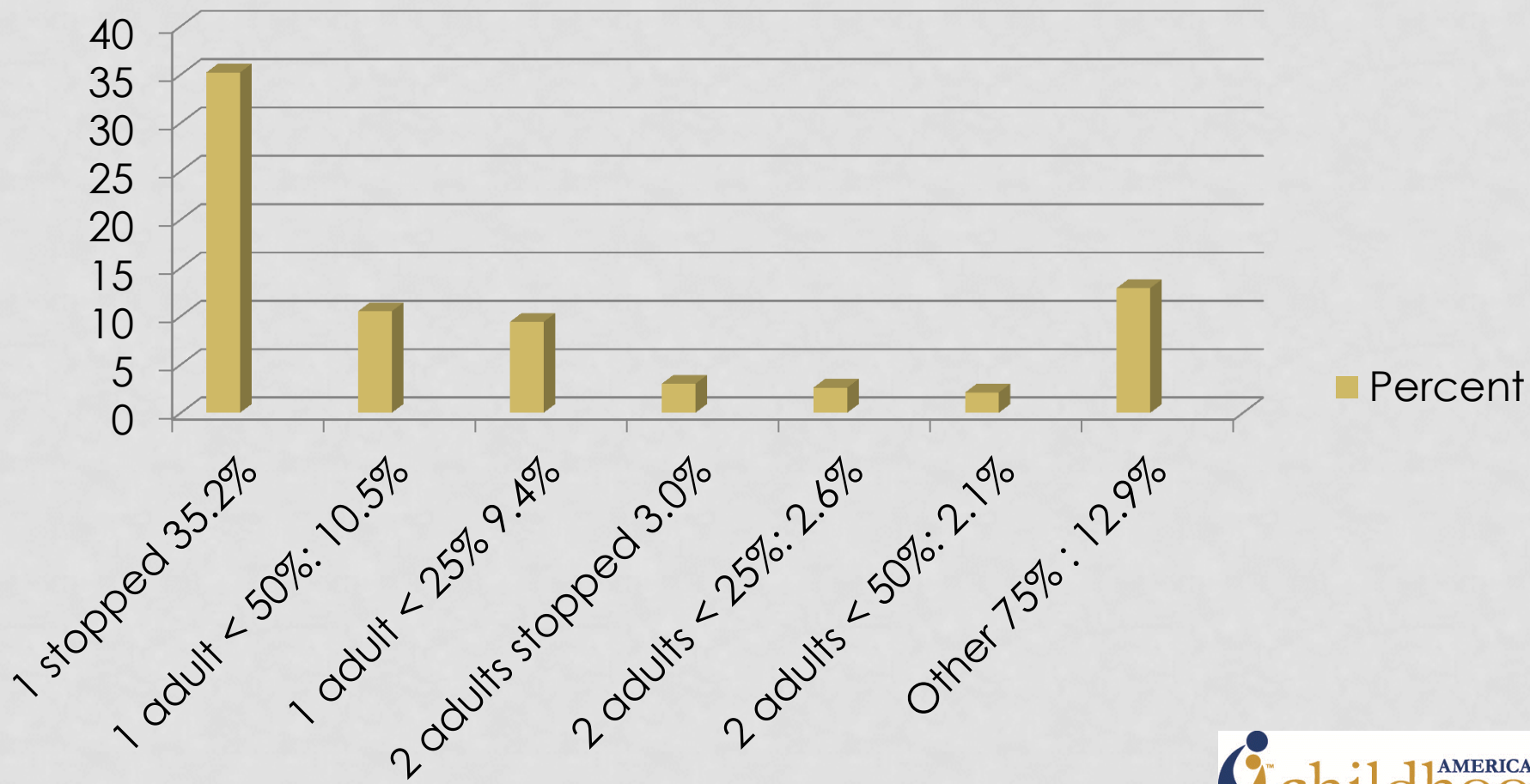
IMPACT OF DIAGNOSIS ON EMPLOYMENT

**No
impact
20.7%**

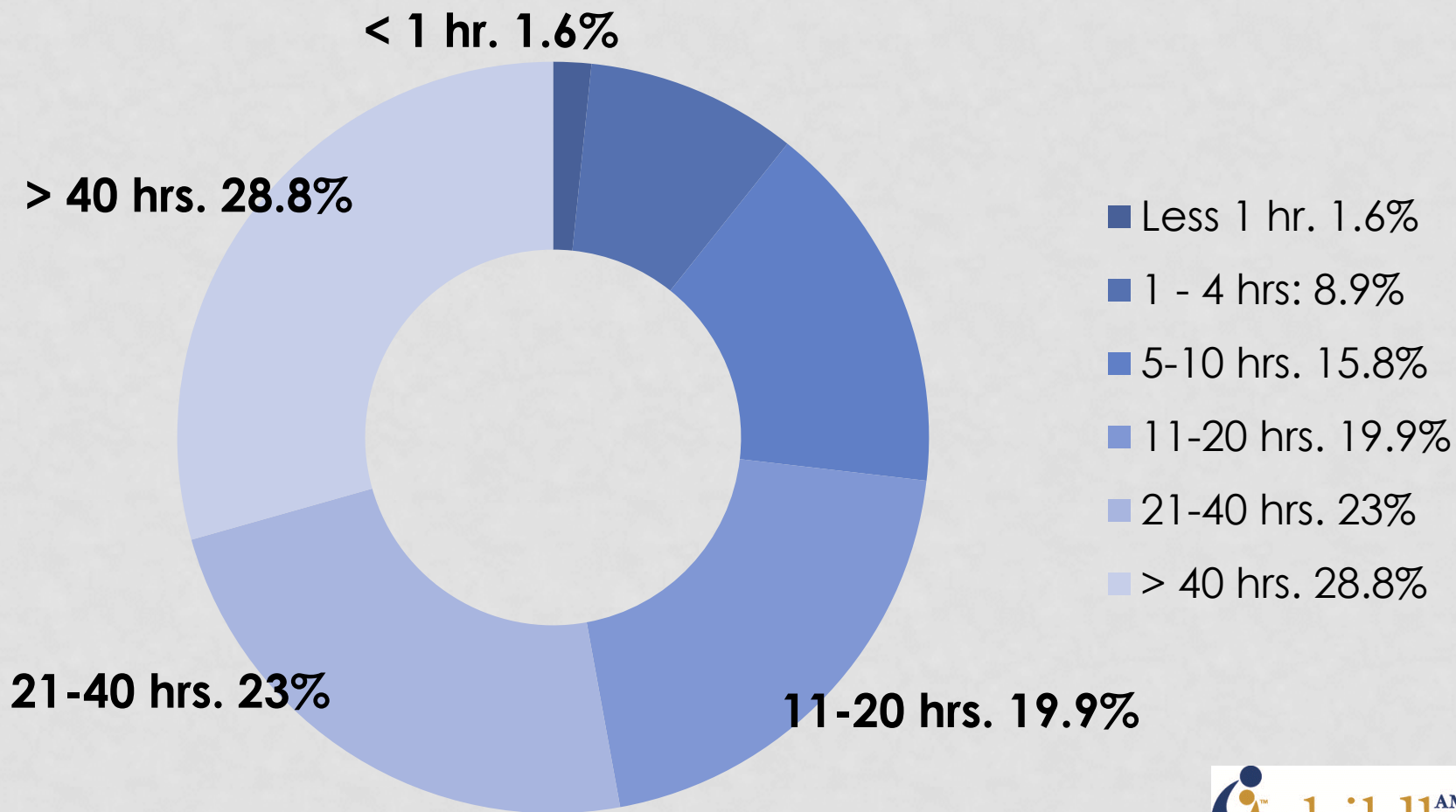


**Stopped Work or
cut back on work
75.7%**

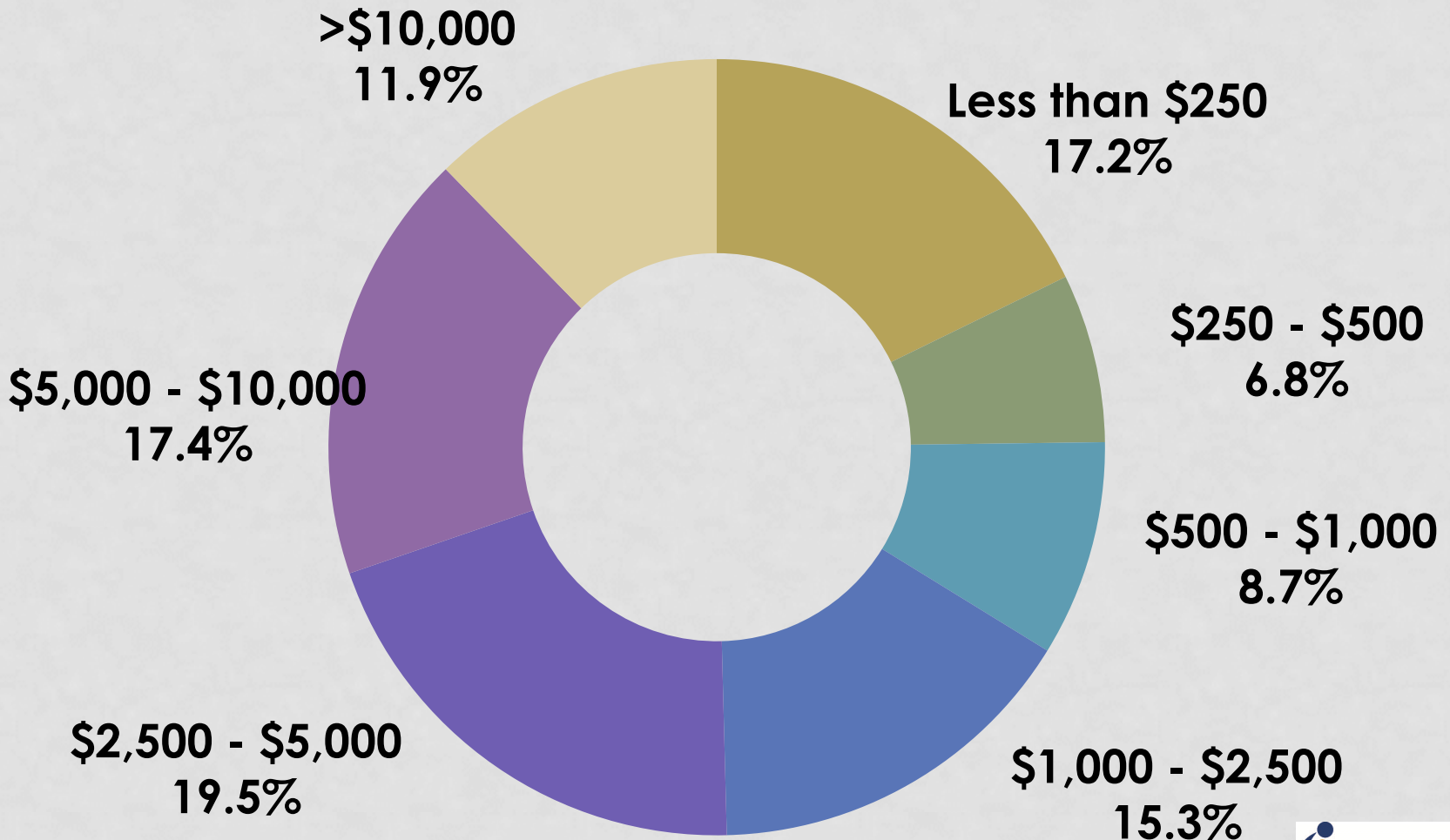
PARENTAL WORK REDUCTION



TIME SPENT PROVIDING CARE OF CHILD WITH CANCER



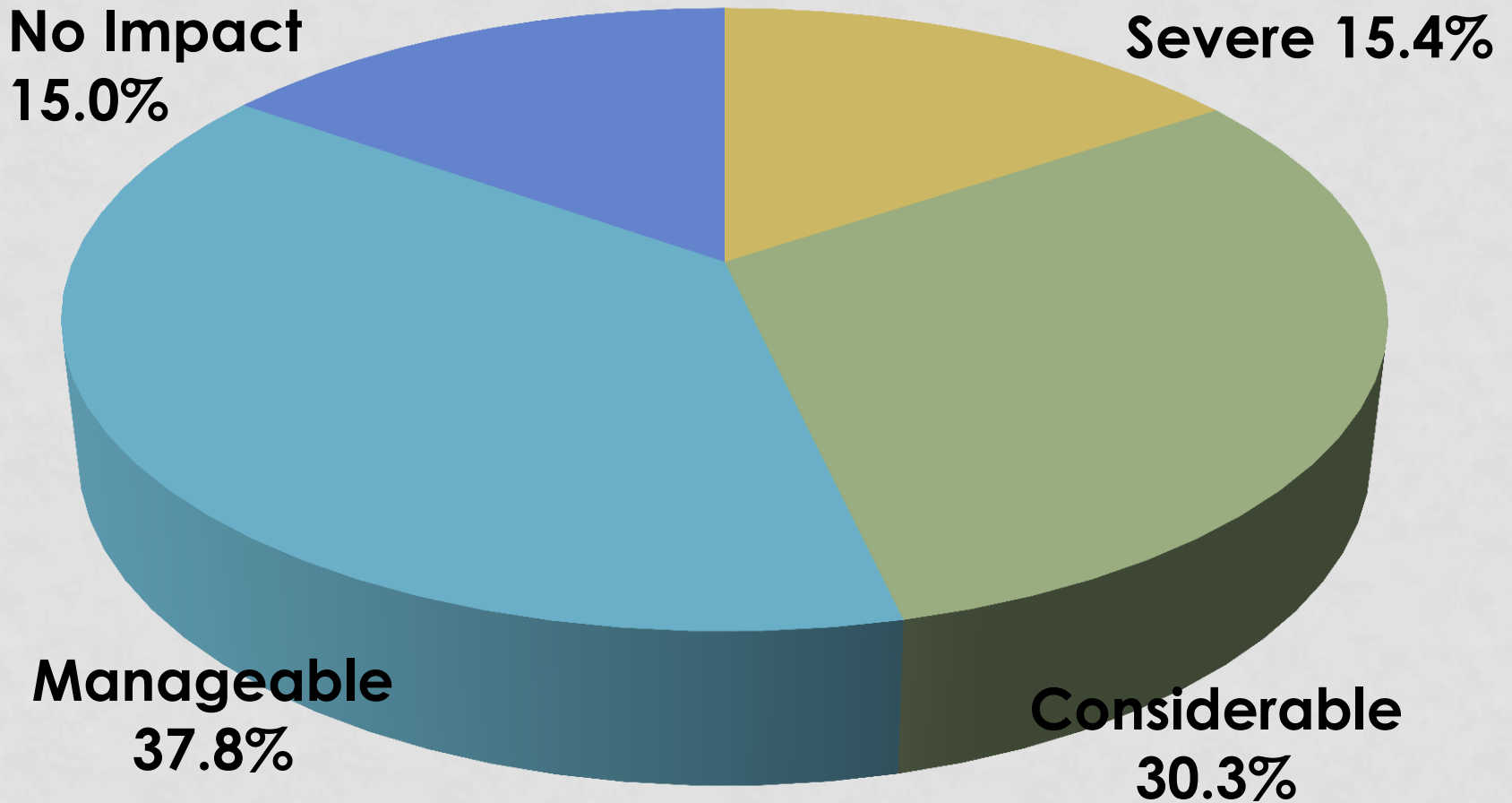
ANNUAL OUT-OF-POCKET EXPENDITURES FOR CARE OF CHILDREN WITH CANCER



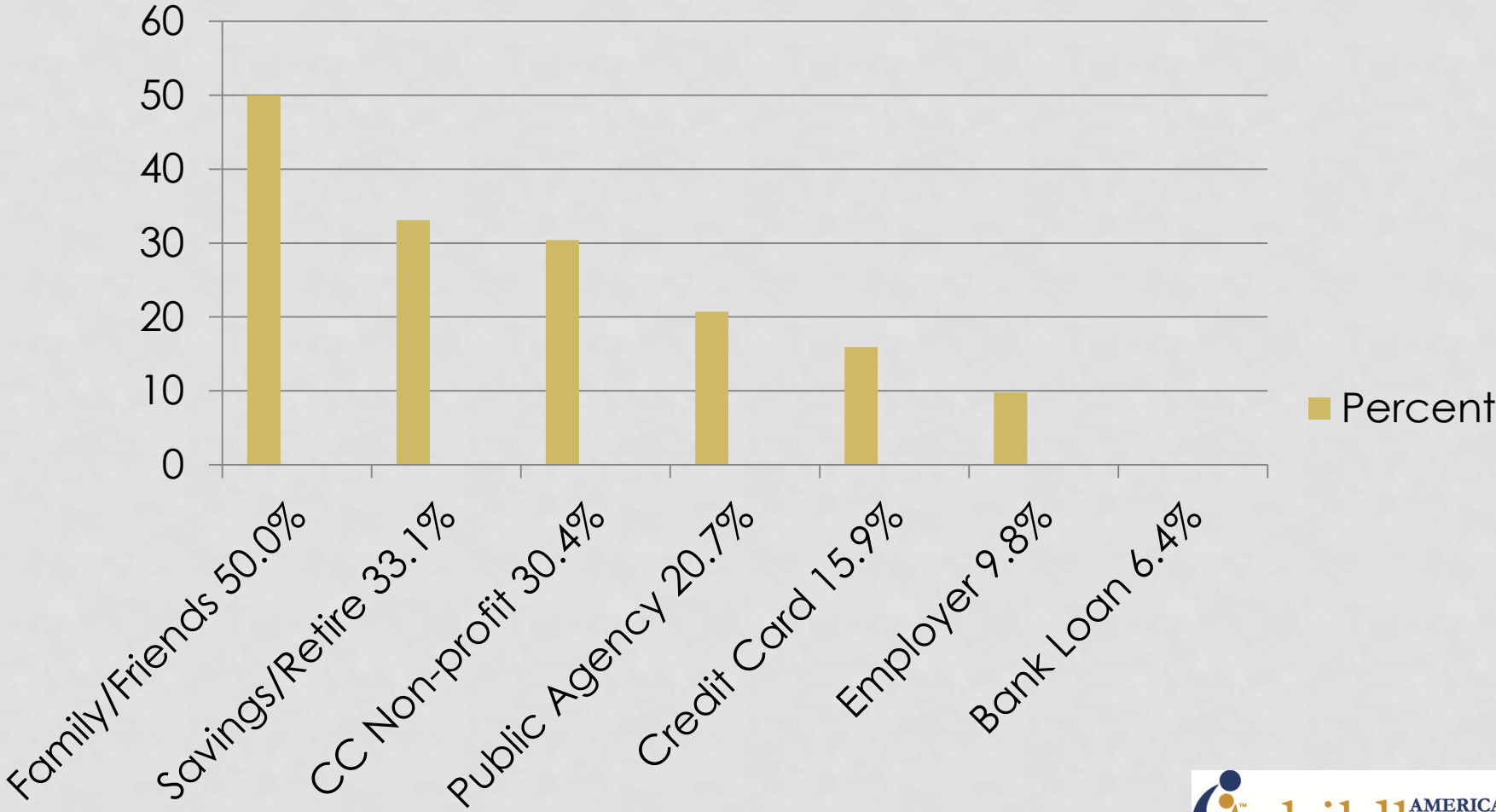
EXPENDITURES

- **Co-pays (meds, appointments, treatments, example \$250 for each LP, out of network)
- **High deductible (example first \$5,000 annually)
- Medications
- Supplies, equipment (wheelchair, support shoes,
- Travel to treatment (transportation, lodging)

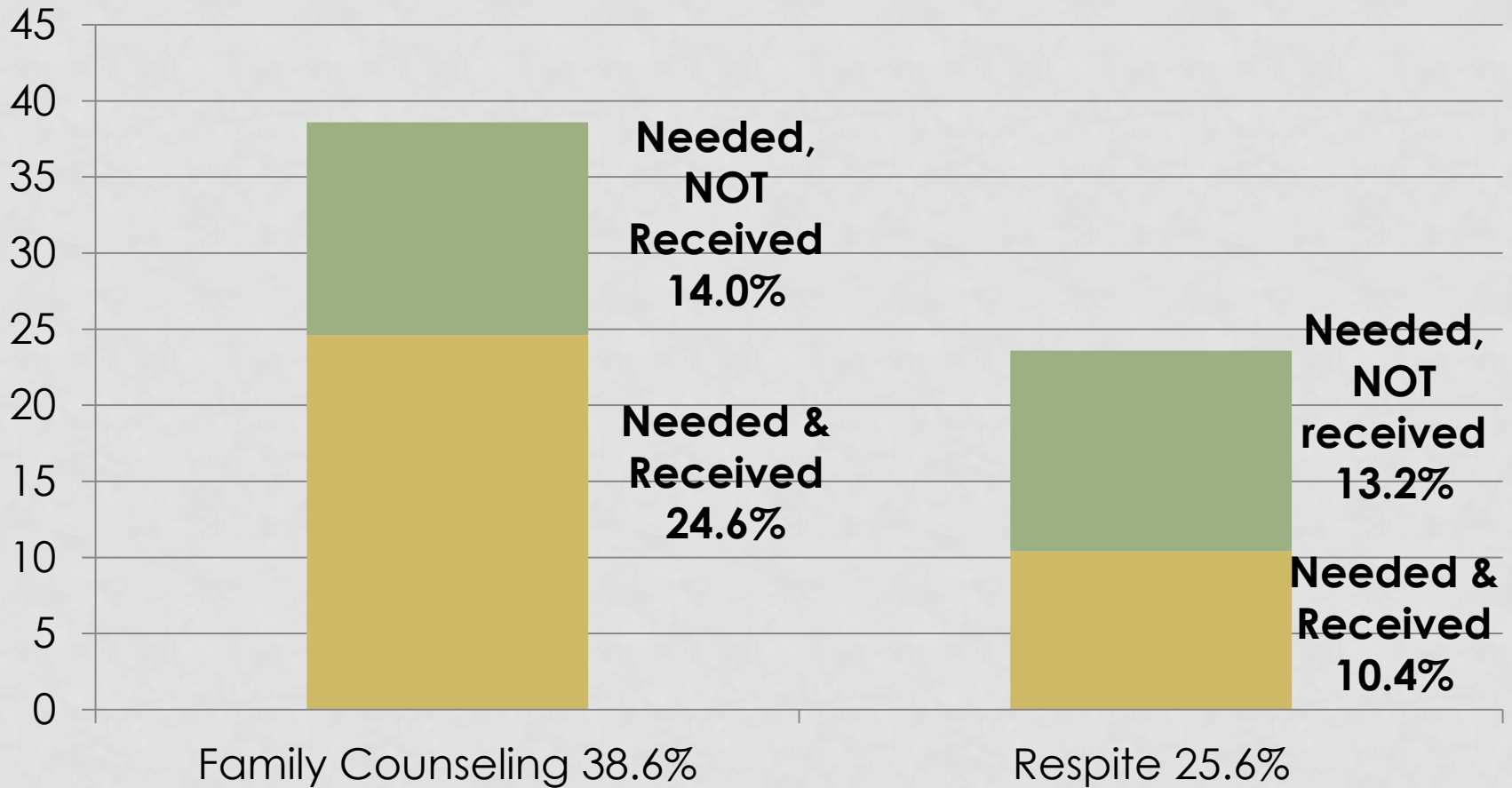
FINANCIAL PROBLEMS: 83.5%



SOURCE OF FINANCIAL HELP



CC FAMILIES NEEDING SUPPORT SERVICES



SUMMARY

Childhood cancer is devastating to the family with the impact felt financially and emotionally for a very long time.

There is a significant opportunity and responsibility to support families with information, financial assistance, emotional support, as well as respite care.

“I am of the opinion that my life belongs to the whole community and as long as I live, it is my privilege to do for it whatever I can. I want to be thoroughly used up when I die, for the harder I work the more I live.”

~George Bernard Shaw