

# Life Care Plan Survey 2022: Process, Methods, and Protocols - A 20-year Perspective

Tracy Albee, RN, BSN, LNCC, CLCP, FIALCP

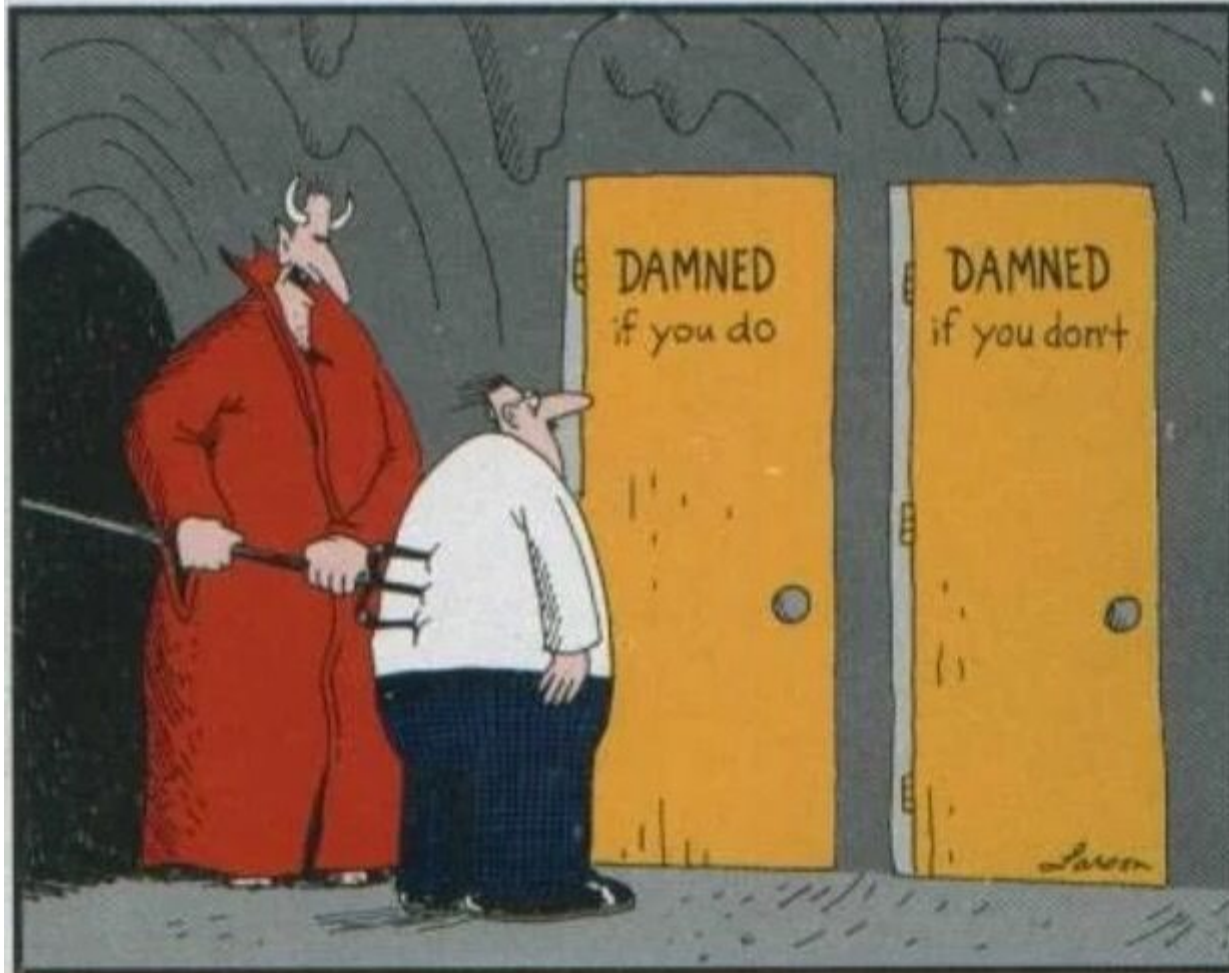
Debbe Marcinko, RN, BSN, MA, CRRN, CCM, CRC, CLCP, CNCLP, LPC

March 10, 2023

American Association of Nurse Life Care Planners

Annual Conference: Taking Care of Business

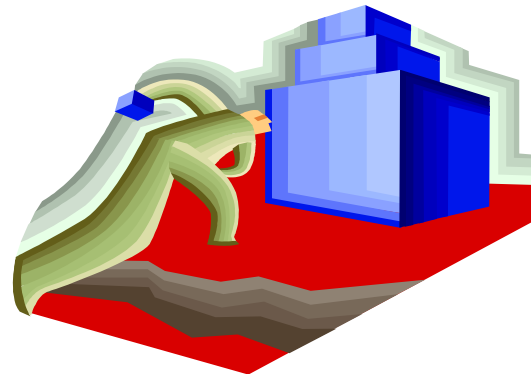
Memphis, TN



**"C'mon, c'mon — it's either one or the other."**

# Survey/Presentation Goals

- Describe the current state of life care planning practices
- Provide data on protocols/procedures and methodologies used by life care planners
- Identify areas of life care planning practice where further definition, refinement and/or research may be necessary

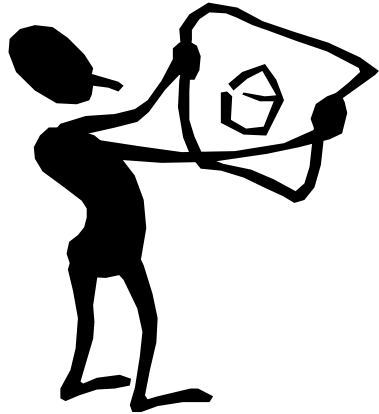


# Research Team

- Ann Neulicht
- Susan Riddick-Grisham
- Tracy Albee
- Mary Barros-Bailey
- Melissa Knott
- Debbe Marcinko
- Nancy Mitchell
- Rick Robinson
- Nick McAfee (Statistician)
- Amber Maxwell (Research Assistant)



# Survey Design



- Literature/Current Issues Reviews
- FLCPRR Letter of Interest/Proposal
- Review/revision of 2001/2009 Survey questions
- Pandemic Survey
- Pilot Surveys
- IRB application/review
- CEU applications
- LCP Survey 2022 (6/15 - 7/28)
- Statistical Analysis
- Dissemination

- Funded by the Foundation for Life Care Planning and Rehabilitation Research (FLCPRR)
- Approved (as exempt) by the Capital University Institutional Review Board (IRB)
- Continuing Education Credits (AANLCP, ICHCC, CRCC)



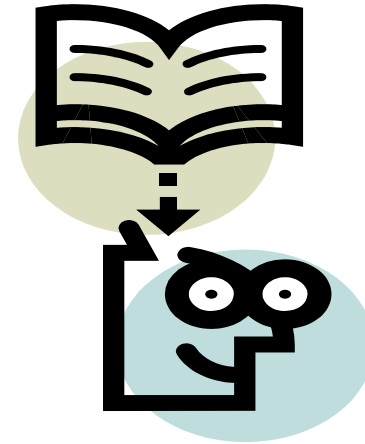
# Questions New to the 2022 Survey

- Sources of e-blasts/invitations
- Answer considering a typical year prior to pandemic
- Complete survey only once
- Average gross annual income
- Professional Liability Insurance
- Age
- Referrals as a dually retained LCP
- Minimum hours to complete a LCP
- Maximum hours to complete a LCP
- Varying rates for different types of cases
- Accept rush/accelerated services
- Differential rates (% higher or lower) for rush/accelerated, travel, non-testifying consultant, research assistance, administrative services
- Last raised rates
- Testimony subject to Motion in Limine or in-trial Voire Dire
- Photo release signed by evaluatee
- Only make recommendations within SOP
- Prepare questionnaire for physicians, allied health/education professional
- Consult with allied health/education professionals
- Team with a LCP from another discipline to develop or review LCP for same evaluatee
- Definitions of charge and cost
- Personal contacts (calls, emails, etc.) to obtain costs
- Inclusion of ancillary costs such as assemble, delivery/membership services, tax
- Use of online resources for item costs
- If LCP report not signed, explain
- Contact by a trust or another entity to determine if LCP is being followed
- Asked to implement LCP
- Plans to actively transition to retirement; stop accepting referrals
- CRC CEU evaluation questions



# Operational Definitions

- Counseling v Rehabilitation Counseling
- MD v PhD
- Motion in Limine
- Testifying Expert
- Non-Testifying Consultant
- Evaluee
- Routine
- Life Care Plan





# Pilot Reviewers

- Nancy Bond
- Jodi Fischer
- Nick McAfee
- Sarah Malloy
- Tricia Morrison
- Andrea Nebel
- Victoria Powell
- Karen Preston
- Elizabeth Zaras



# E-Blasts (AANLCP, IARP, ICHCC)

**LCP SURVEY 2022**  
Process, Methods & Protocols: A 20-Year Perspective

**NOW OPEN!**

**CEUS APPROVED**

Survey Link: <https://www.surveymonkey.com/r/QLRV8VC>

Your input is important! This survey builds on those completed in 2001 & 2009, to capture long-term trends, describe the current state of practice, & advance LCP practice into the future!

This survey is funded through a grant provided by the Foundation for Life Care Planning and Rehabilitation Research (FLCPRR)

**LCP SURVEY 2022**  
Process, Methods & Protocols: A 20-Year Perspective

**CEUS APPROVED**

**#ICYMI**  
IN CASE YOU MISSED IT

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## LIFE CARE PLANNING SURVEY 2022

The "LCP Survey 2022: Process, Methods & Protocols - A 20-Year Perspective" will launch soon!

This survey will build on the LCP practice surveys conducted in 2001 & 2009. We aim to capture long-term trends, describe the current state of practice, & advance LCP practice into the future.

**Your input is important - watch for the survey link via email!**

This survey is funded through a grant provided by the Foundation for Life Care Planning and Rehabilitation Research (FLCPRR)

**LCP SURVEY 2022**  
Process, Methods & Protocols: A 20-Year Perspective

**REMEMINDER!**

**CEUS APPROVED**

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**LCP SURVEY 2022**  
FINAL REMINDER! SURVEY CLOSES JULY 27th!

**TIME IS RUNNING OUT!**

**CEUS APPROVED**

Survey Link: <https://www.surveymonkey.com/r/QLRV8VC>

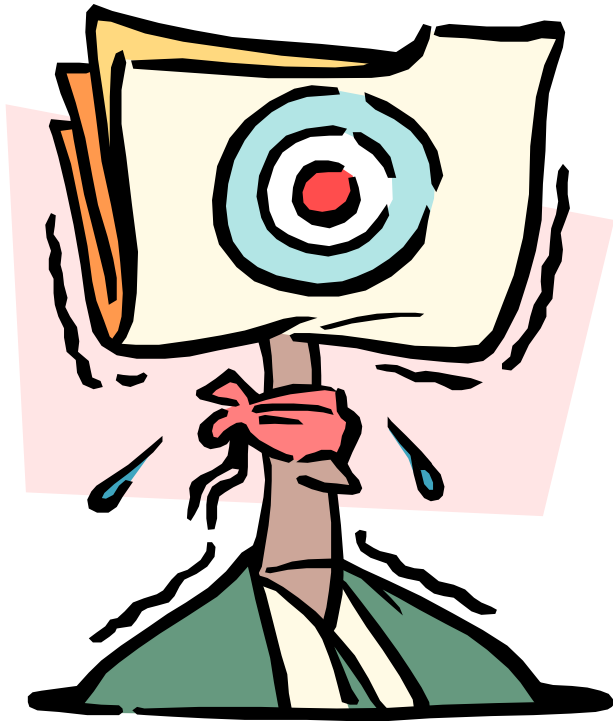
Your input is important! This survey builds on those completed in 2001 & 2009, to capture long-term trends, describe the current state of practice, & advance LCP practice into the future!

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**Preliminary Results [Still  
doing analysis]**

# Currently Practicing as a Life Care Planner?



I have completed and submitted at least one life care plan to a referral source in the last year.

- 2022
- 2009
- 2001
- 1980's (PMD workshops)

# Response Rate

- 474 individuals started the survey
- 83.54% (n=396) completed/submitted at least one LCP to a referral source in the last year
- Range of responses to questions: 231 to 372



# The Typical Respondent

- Female
- CLCP
- Member of IARP/ IALCP
- Active member of a Listserv
- Completes up to 20 LCPs per year
- On average, reviews/analyzes 1 - 10 LCPs per year as non-testifying expert
- Only makes recommendations within professional scope of practice
- Includes a medical records review in LCP report
- Documents pre-existing conditions within the report; does not include related costs for goods/services in LCP
- Includes a list of complications (potential and probable) in LCP
- Has not received referrals as a dually retained LCPer
- Has not been asked to team with a LCPer from another discipline to develop or review a LCP for the same evaluatee
- Has not been contacted by a trust or another entity to determine LCP is being followed
- Has not been asked to implement a LCP



# Testimony Experience

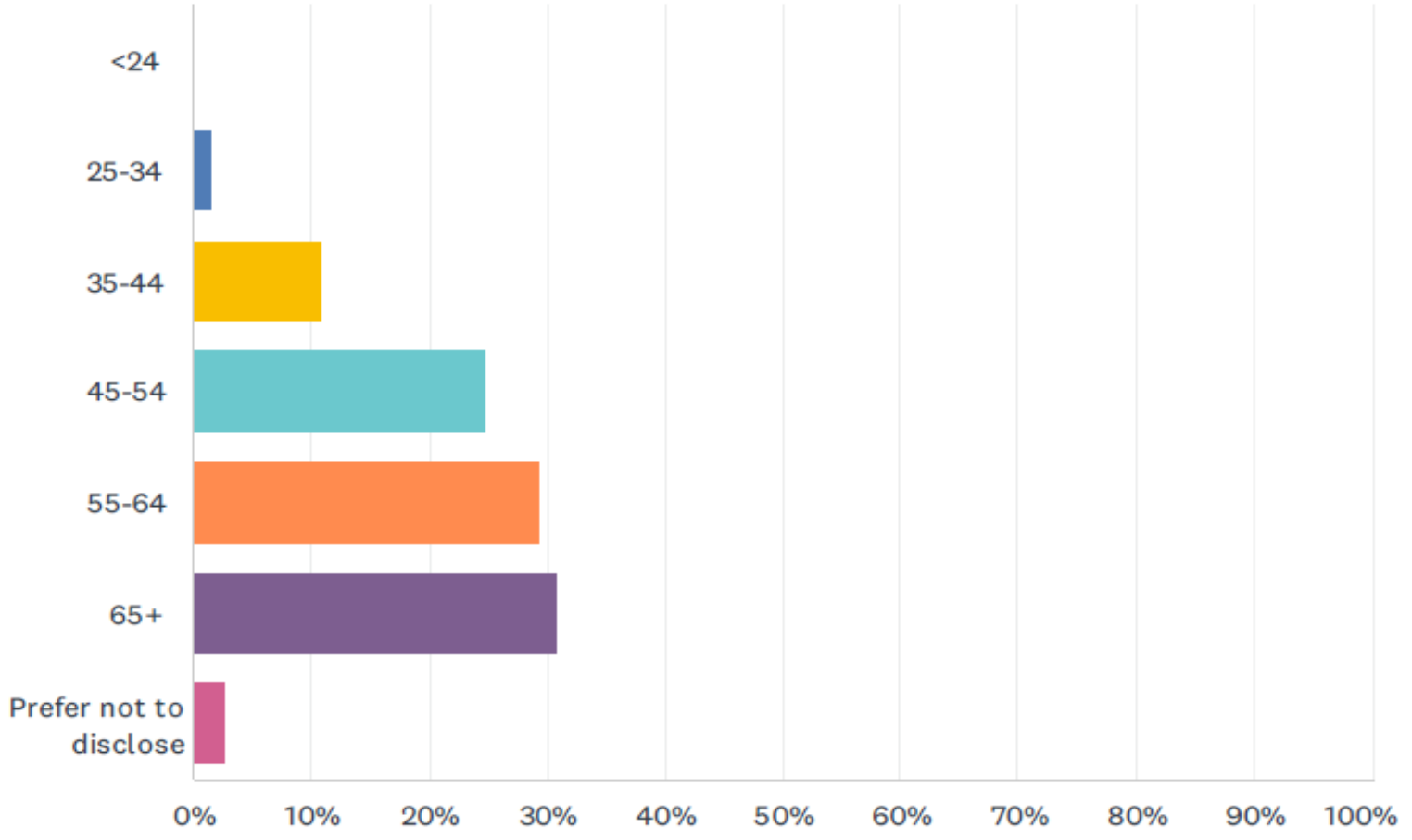
Deposition is the predominant type of testimony

<i>Type</i>	<i>Responses</i>	
Deposition	91.48%	279
State/Provincial Court	88.20%	247
Federal Court	80.98%	269
Workers' Compensation Hearing	71.15%	217
Mediation/Arbitration	72.13%	220
Marital Dissolution	68.20%	208
Other	21.97%	67

Majority (59%) have not had testimony subjected to motion in limine (USA) or in-trial voire dire (CAN)

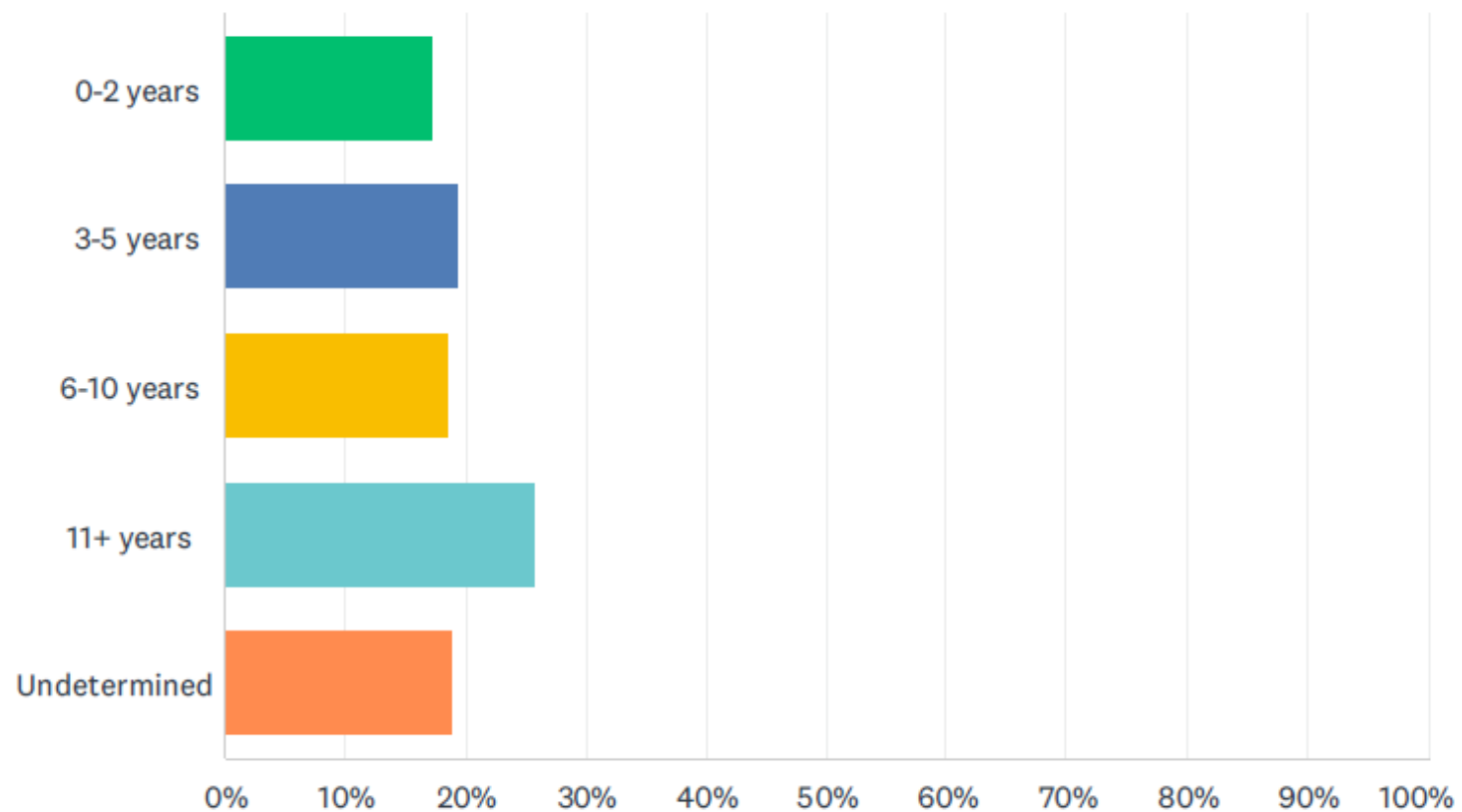


# Age





# Actively transition to retirement (reduce number of files/work hours)



# Business Practices



- Owner/independent practice
- Carries professional liability insurance
- Attorneys are the primary source of referrals
- LCPs prepared primarily for personal injury/accident cases, followed by medical malpractice, then chronic illness
- Not listed with an expert witness service
- Requires a signed agreement (or letter of engagement) prior to accepting a case
- Requires a retainer before initiating work on a case
- Accepts rush/accelerated services
- Most common use of others (contracted workers, other staff) is to assist with clerical, cost research, proofreading
- Typically contacts referral source to resolve non-payment of bills
- Maintains closed case files for 7 years
- GOALS:
  - 2001: Increase LCP referrals
  - 2009: Increase efficiency and referrals
  - 2022: Increase efficiency

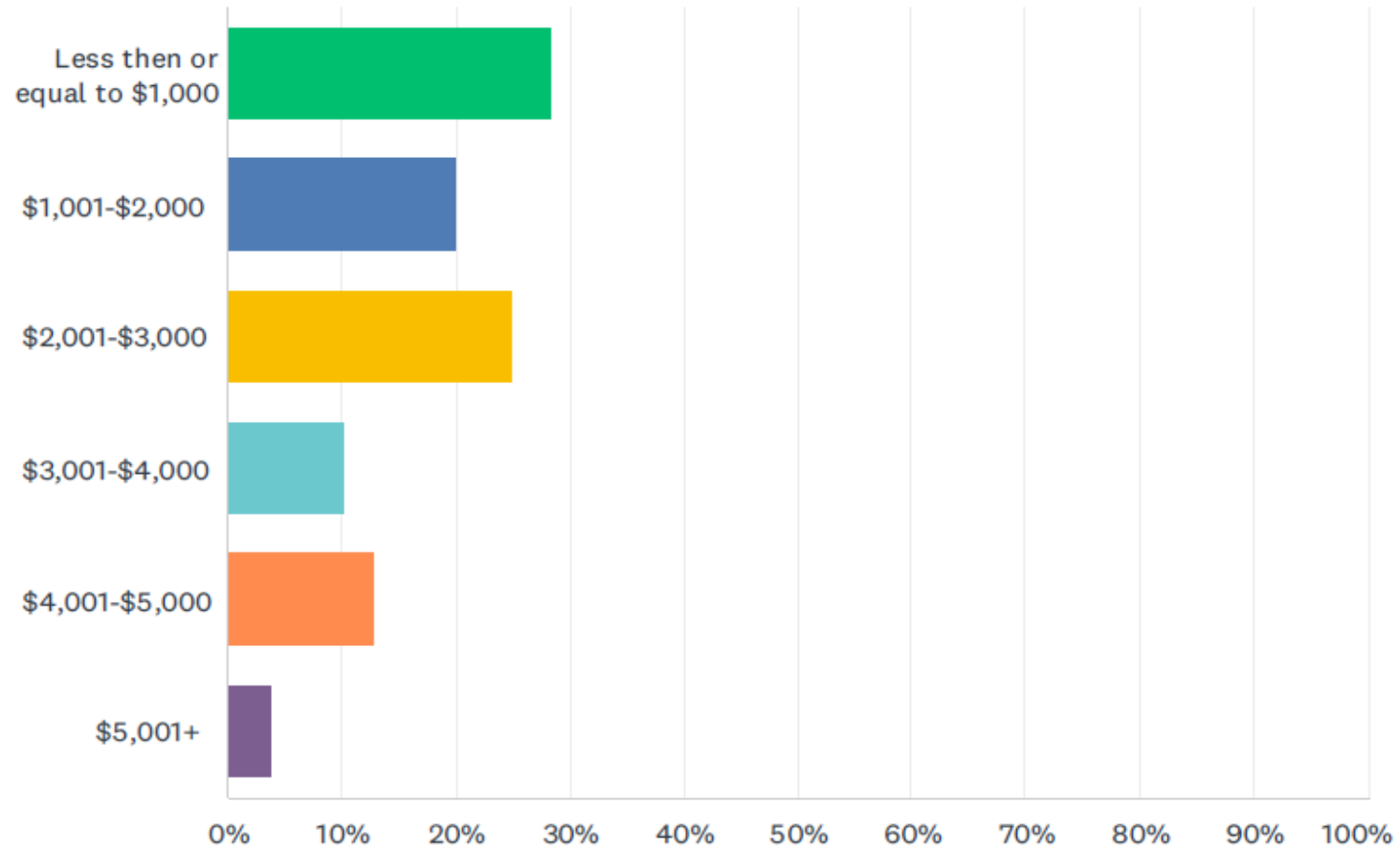
# Billing

## A majority of respondents

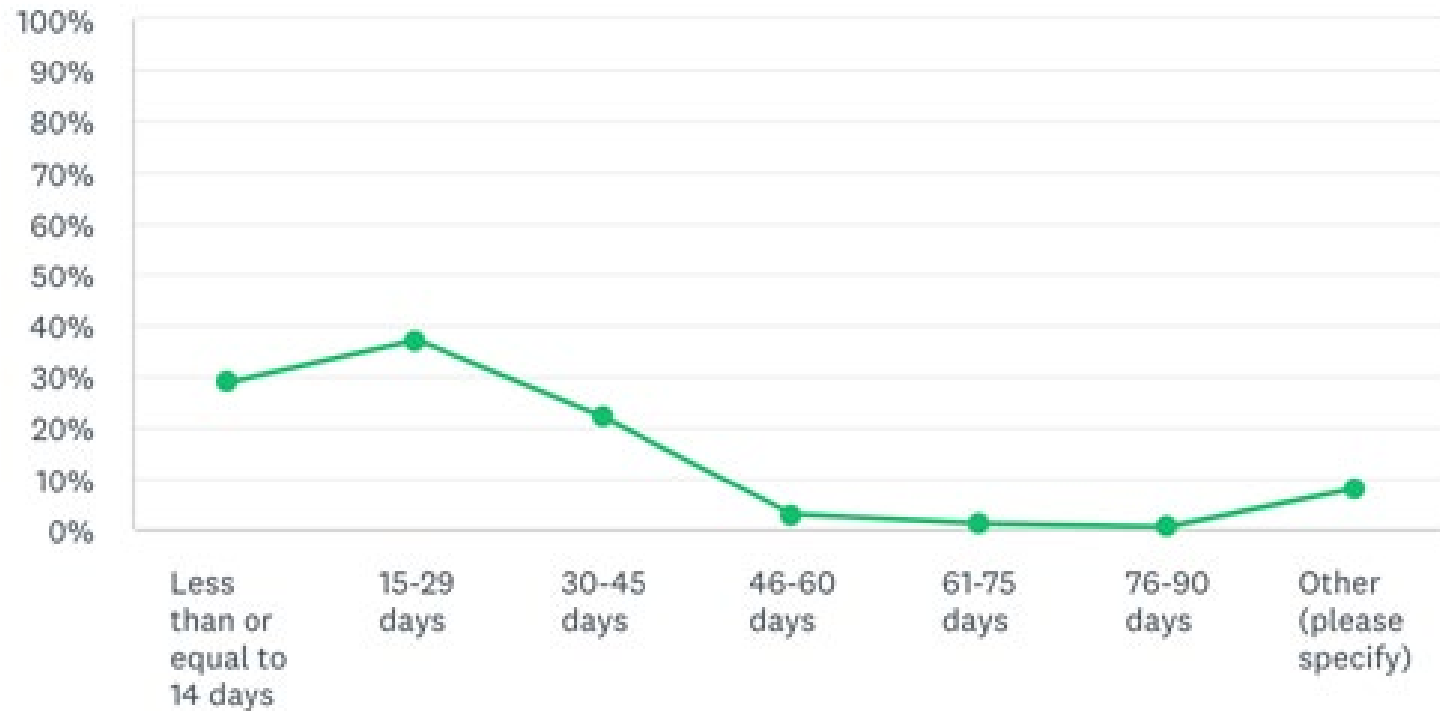
- Bill by the hour
- Charge a different rate for:
  - court/deposition appearance
  - rush/accelerated services
- Do not charge a different rate for:
  - different types of cases
  - travel
  - serving as a non-testifying consultant
  - research assistance services
  - administrative services



# Retainer Amount

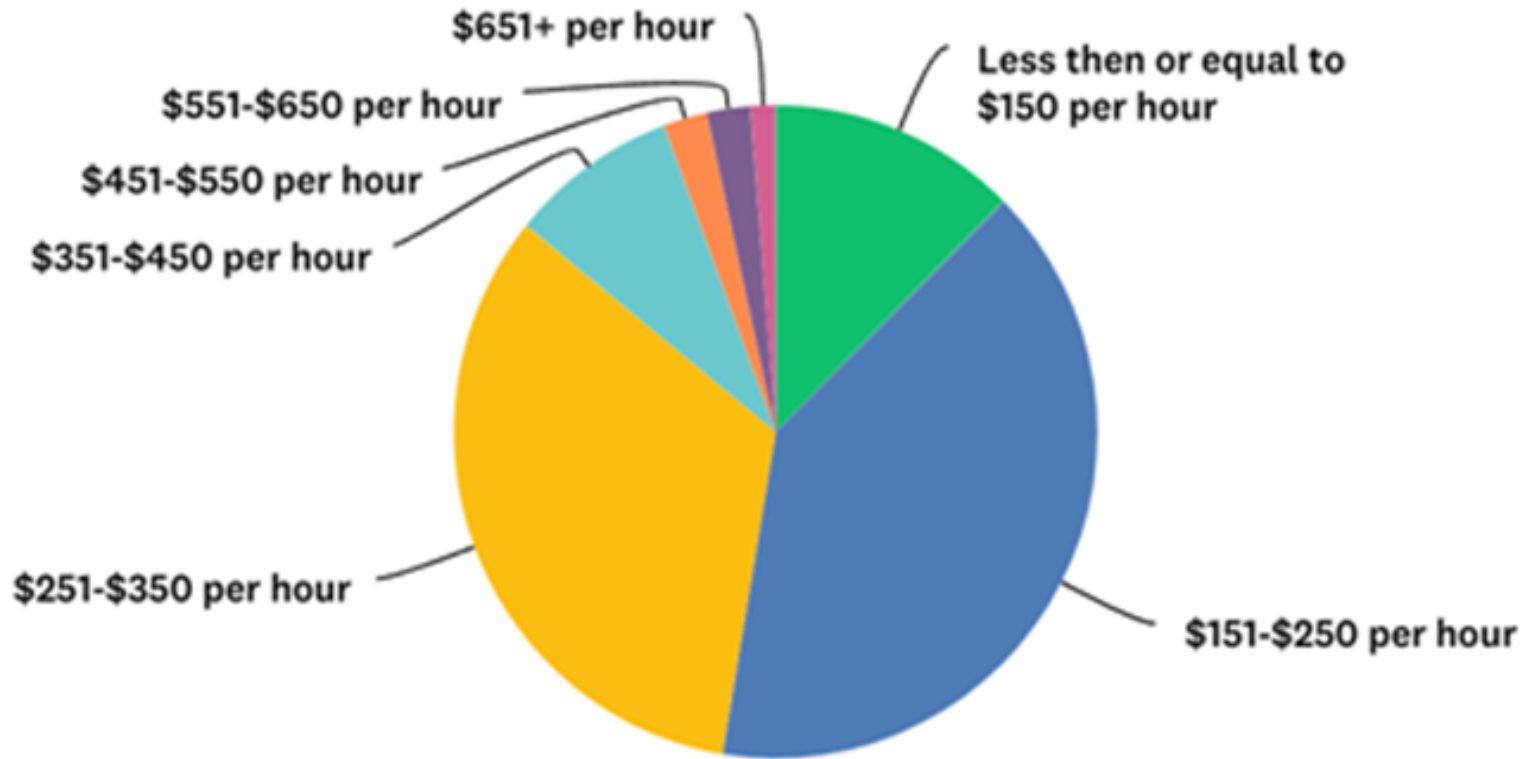


# Definition of Rush/Accelerated Services



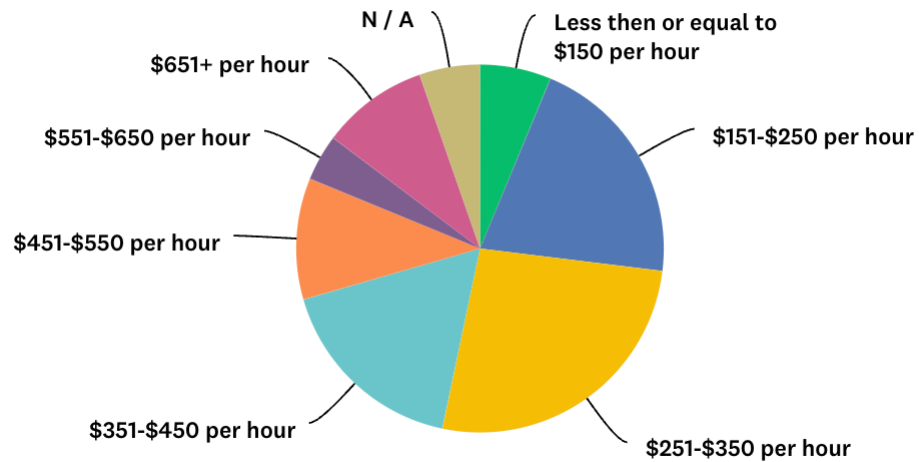
# Hourly Fees

## Case Analysis, Preparation, Peer Review, Reports

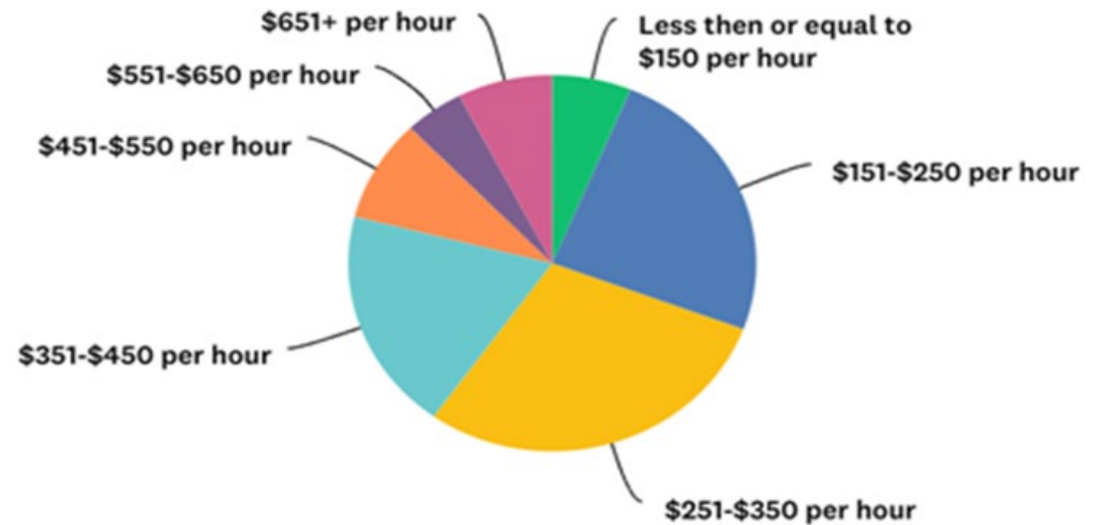


# Hourly Fees: Testimony

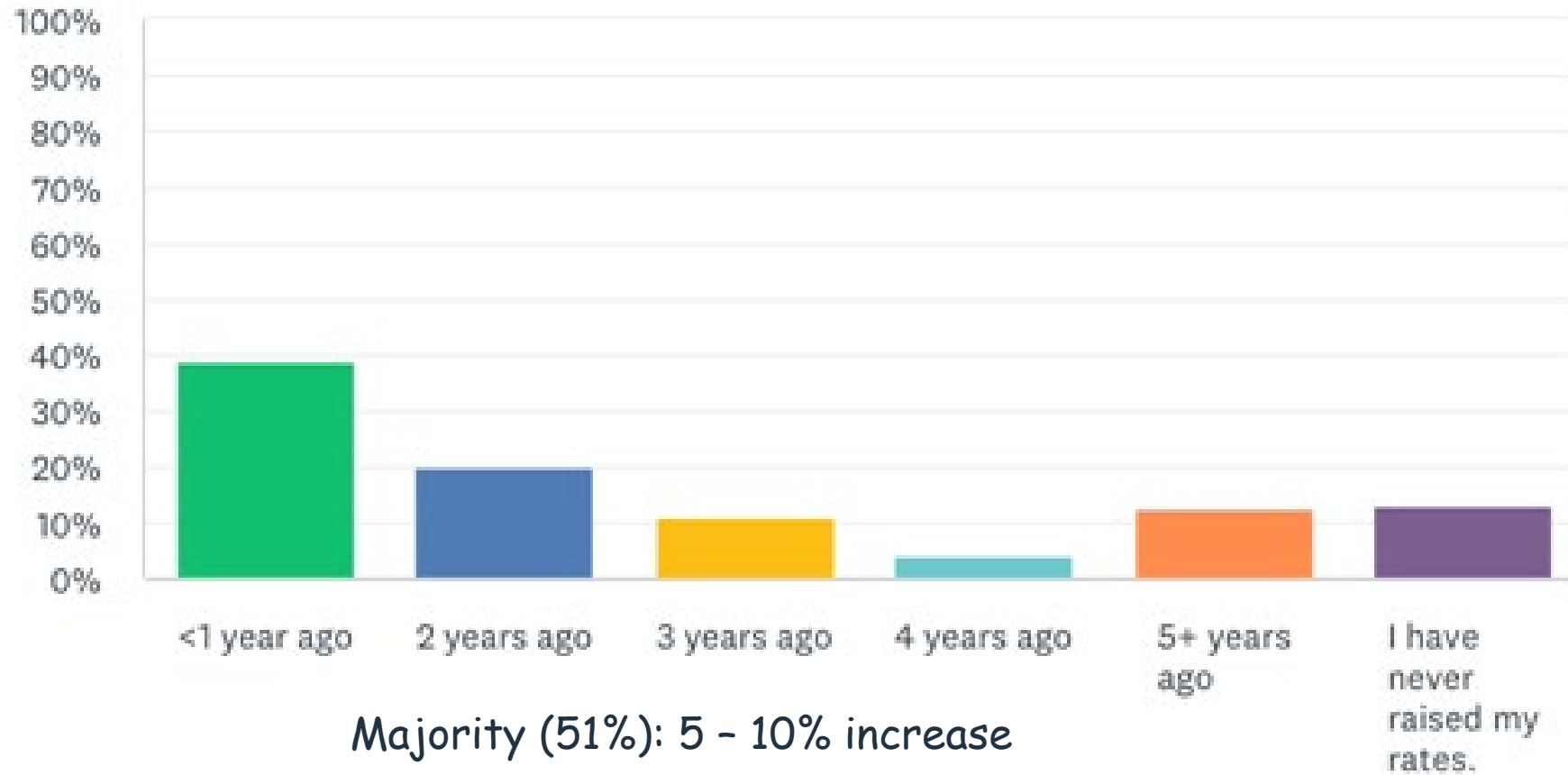
## Deposition



## Court

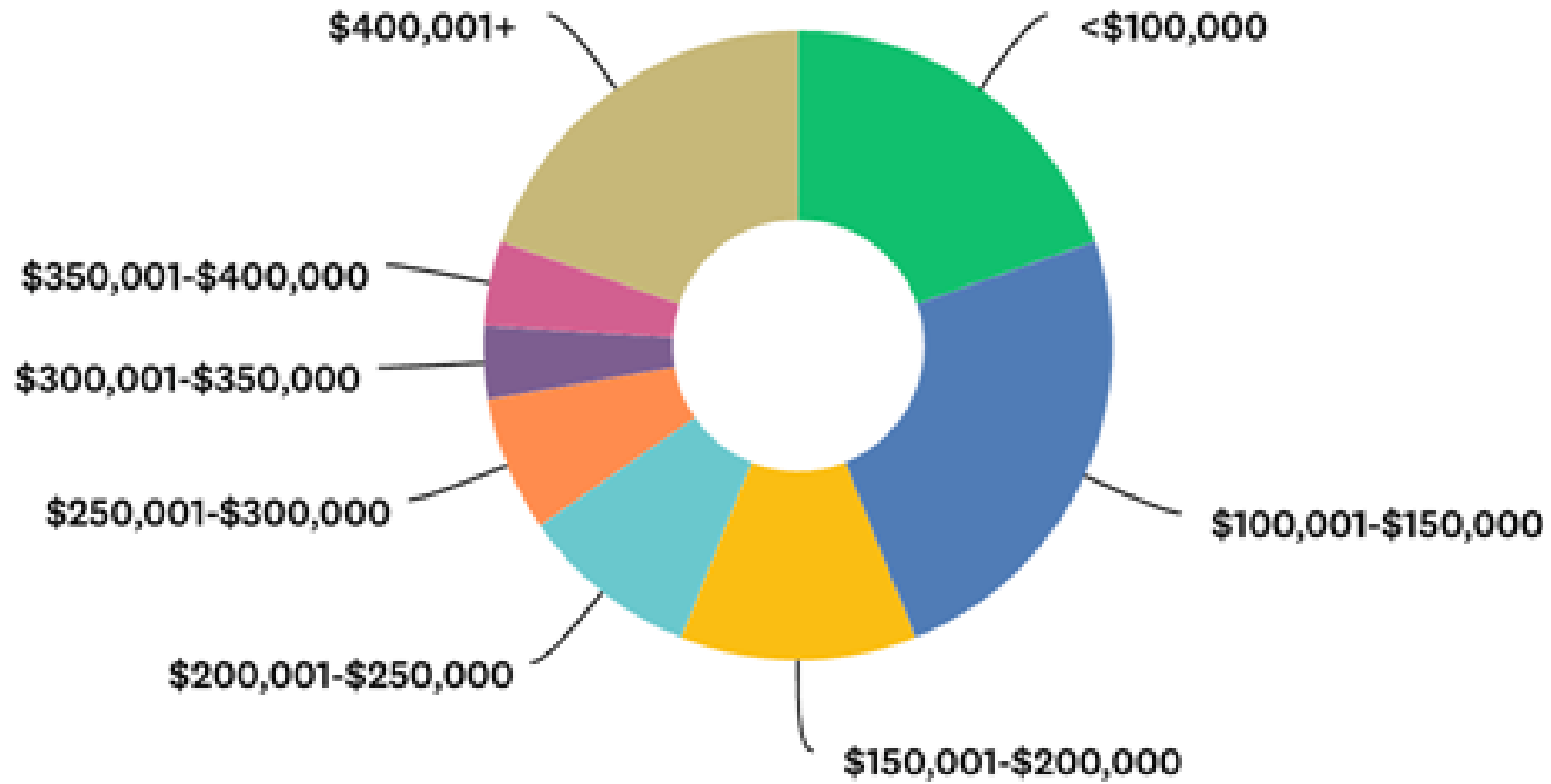


# Last Rate Increase

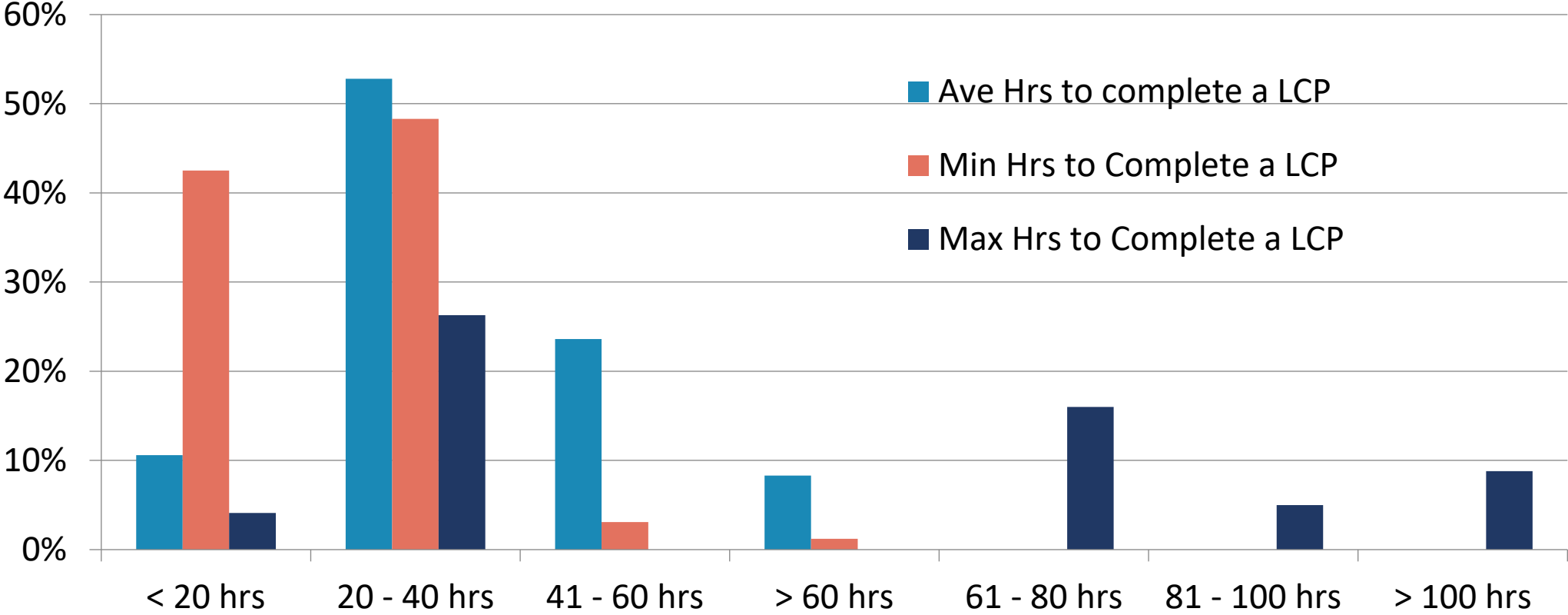




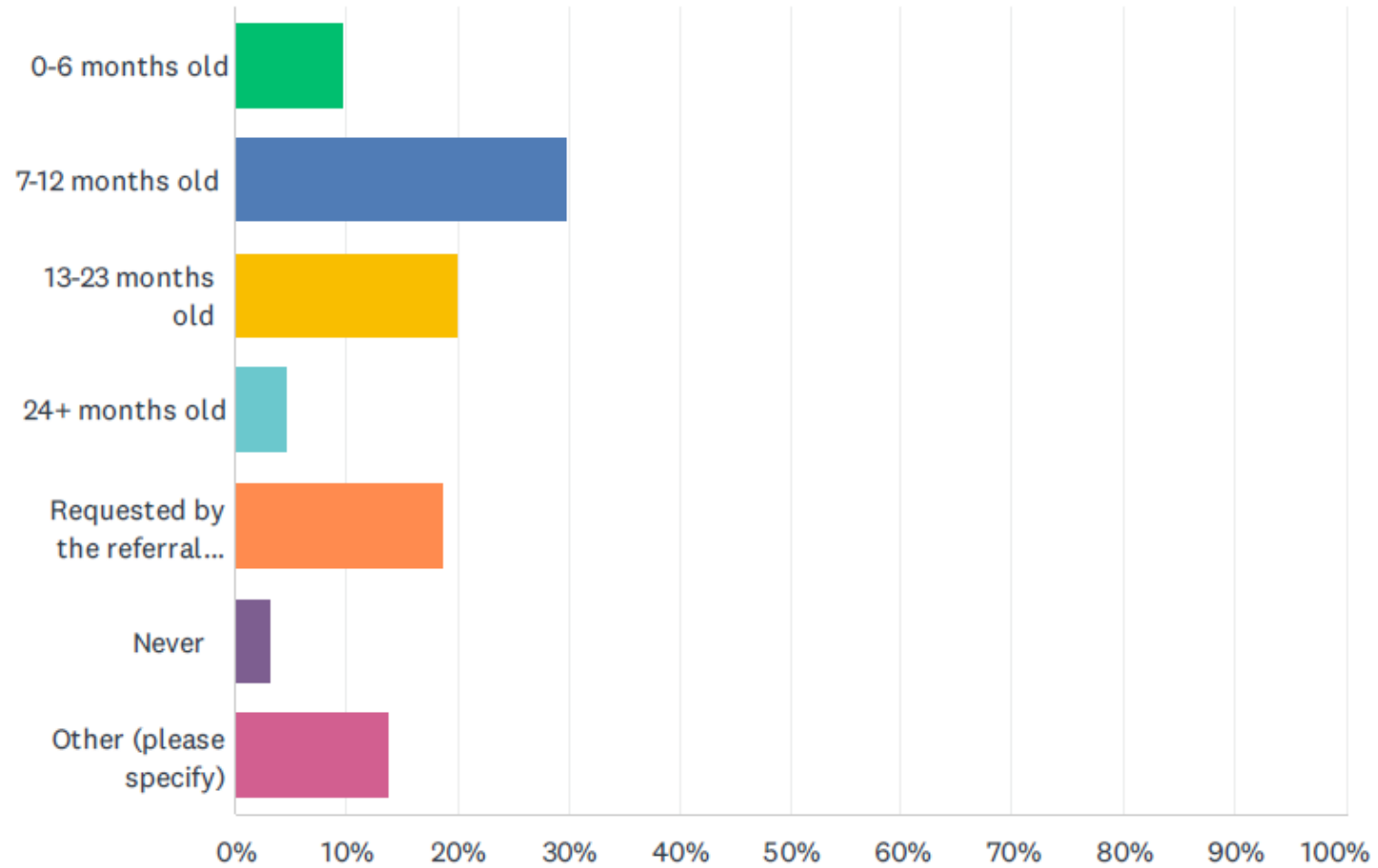
# Average Gross Annual Business Income



# How long does it take to complete a LCP?



# Prior to Testimony, Routinely Update a LCP if



# Majority of Respondents (76 - 100%)

- Use a structured interview form
- Independently request a signed consent form (plaintiff referred cases)
- Review medical records
- Review/use clinical practice or standard of care guidelines
- Consult with physician(s) in addressing medical recommendations
- Include a discussion/rationale of/for recommendations in the LCP
- When applicable, consider more than one residential care option
- Consider the time that a parent would normally be expected to perform parenting duties when recommending in-home supervision for a pediatric evaluatee
- Include discussion or reference to life expectancy
- Sign the Life Care Plan



# Majority of Respondents Routinely

- use standardized questionnaires and/or checklists to document information from evaluatee, family, allied health professionals
- use standardized checklists and/or questionnaires to manage the life care planning process
- obtain more than one cost quote on individual items or services

BARTHEL INDEX		
	<i>With Help</i>	<i>Independent</i>
1. Feeding (if food needs to be cut up = help)	5	10
2. Moving from wheelchair to bed and return (includes sitting up in bed)	5-10	15
3. Personal toilet (wash face, comb hair, shave, clean teeth)	0	5
4. Getting on and off toilet (handling clothes, wipe, flush)	5	10
5. Bathing self	0	5
6. Walking on level surface (or if unable to walk, propel wheelchair)	10	15
*score only if unable to walk	0*	5*
7. Ascend and descend stairs	5	10
8. Dressing (includes tying shoes, fastening fasteners)	5	10
9. Controlling bowels	5	10
10. Controlling bladder	5	10

A patient scoring 100 BI is continent, feeds himself, dresses himself, gets up out of bed and chairs, bathes himself, walks at least a block, and can ascend and descend stairs. This does not mean that he is able to live alone: he may not be able to cook, keep house, and meet the public, but he is able to get along without attendant care.

# Majority of Respondents Do Not

- Serve as a case manager, counselor, therapist, or treatment provider on a case before or after a LCP has been developed
- Video the evaluatee (not including day-in-the-life videos)
- Participate in the development/ presentation of day-in-the-life videos
- Have a photo release signed by the evaluatee
- Provide a copy of the LCP to the evaluatee and/or family
- Contact evaluatees/families to determine if the LCP is being followed



# Publications, Sources, Texts

## Top 4:

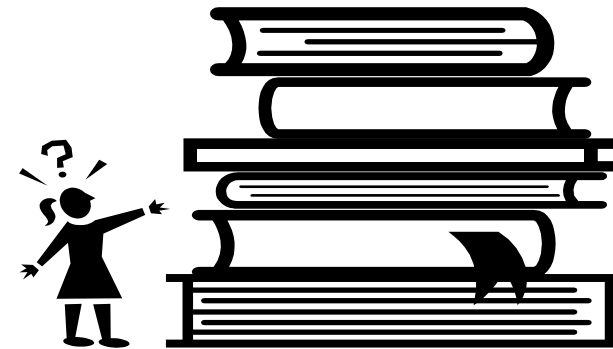
- *Life Care Planning and Case Management Handbooks* or other Life Care Plan or Rehab Related Textbooks (72)—**Life Care Planning Across the Lifespan coming this summer of 2023]**
- *Journal of Life Care Planning* (42)
- Professional publications/medical journals/peer-reviewed journals/medical textbooks (28)
- Clinical Practice Guidelines (20)

## Honorable Mentions:

- National Vital Statistics Reports / CDC (16)
- AANLCP Journal (13)
- Online Websites (13)
- Standards of Practice (11)
- A Core Curriculum For Nurse Life Care Planning (9)

## Concern...?

- "None" Or "N/A" (11)



# ...Some Answers Included Cost Sources

## Top 4:

- Fair Health (13)
- PMIC (12)
- Physicians Fee Reference (12)
- DME and Pharmacy Costing Sources [GoodRX, Drugs.com, SpinLife] (7)

## Honorable Mentions:

- American Hospital Directory (6)
- Context4healthcare (5)
- CMS.gov (4)
- VA database (4)
- Genworth Cost of Care (4)

## Stand Alone Answers that may be Unfamiliar:

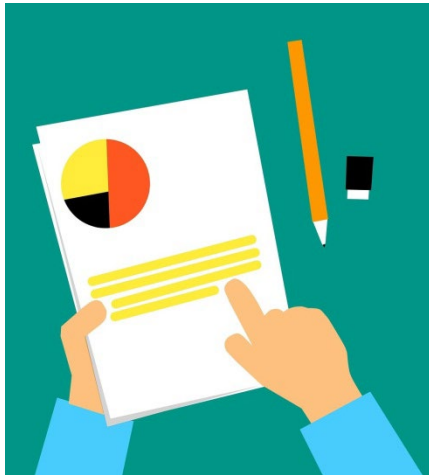
- White Paper on UCR charges
- Cost of Food
- Redbook
- BlinkRx



# Testifying Expert's Report

## Not Included:

- Clinical Practice Guidelines (20.9%)
- Collateral sources (33.47%)
- Financial profile (44.77%)
- Nursing diagnoses (46.64%)
- Pictures (33.89%)
- Rule 26 disclosure (44.26%)



## Majority include (76 -100%):

- Beginning/ending dates for items/services
- Day routine/schedule
- Date of first contact
- Date of LCP
- Date of referral
- DME list
- Evaluations requested
- Frequency/replacement schedule
- Functional Abilities
- Location of Interview
- LCP tables/charts
- Medical diagnoses
- Medical summary/chronology
- Medication Regimen
- Narrative Report
- Providers/professional consults
- Psychosocial/psychiatric diagnoses

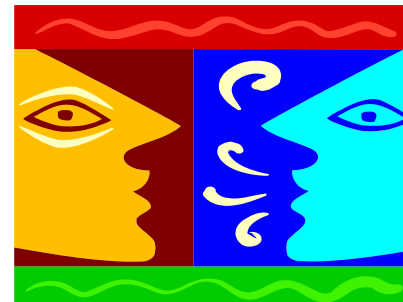
# Testifying Expert's Report (CONTINUED)

## Majority include (76 -100%):

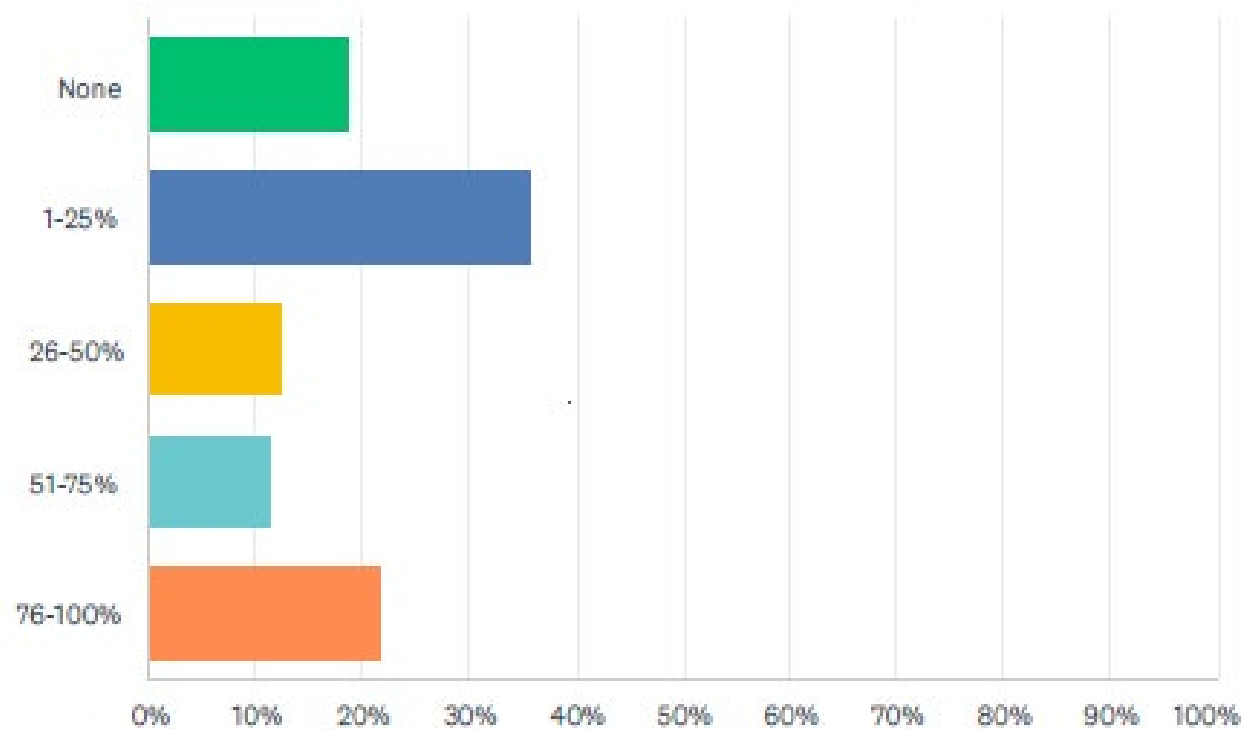
- Rationale/purpose for recommendations
- Reason for referral
- Recommended by (source)
- Records received/reviewed
- Referral source
- Social/environmental profile
- Summary of total costs
- Supply consumption
- Vendor List
- Vocational/Educational Profile
- Other records requested

# Interviews

- Typical location is the evaluatee's home
- Majority of respondents
  - Request a personal interview with evaluatee
  - Spend up to 2 hours conducting an interview
  - Conduct an in-person interview with evaluatee and/or family in cases referred by plaintiff attorneys (76 -100%)
  - Provide written documentation if request for evaluatee interview is denied (76 -100%)

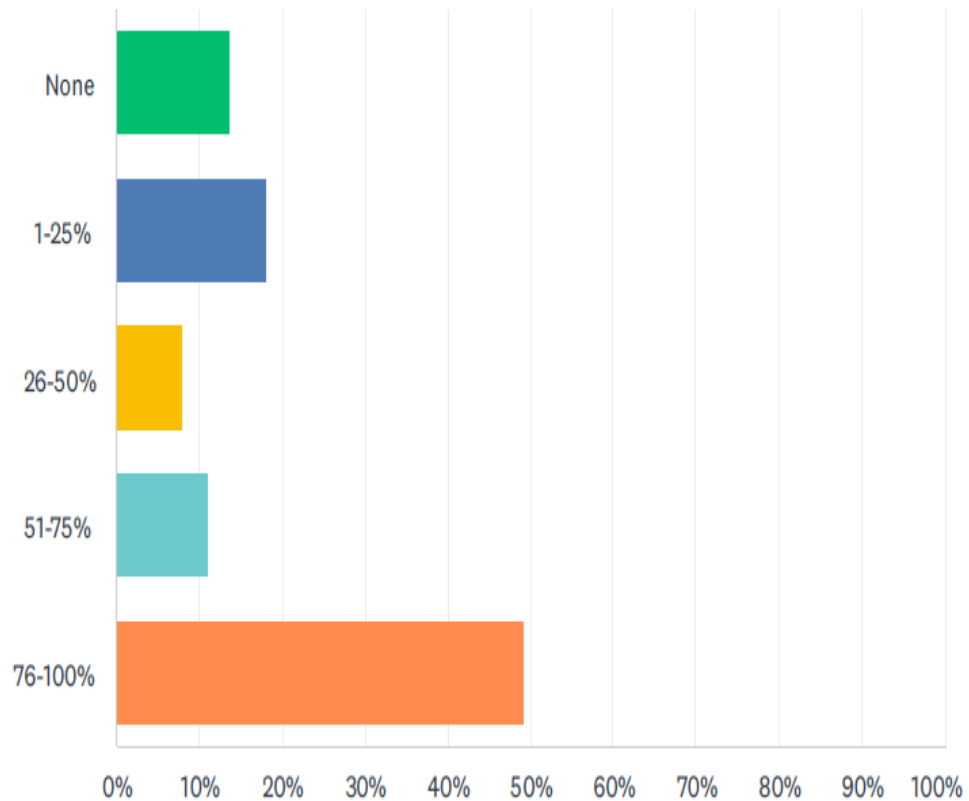


# Conduct In-person Interview for Cases Referred by Defense Attorneys

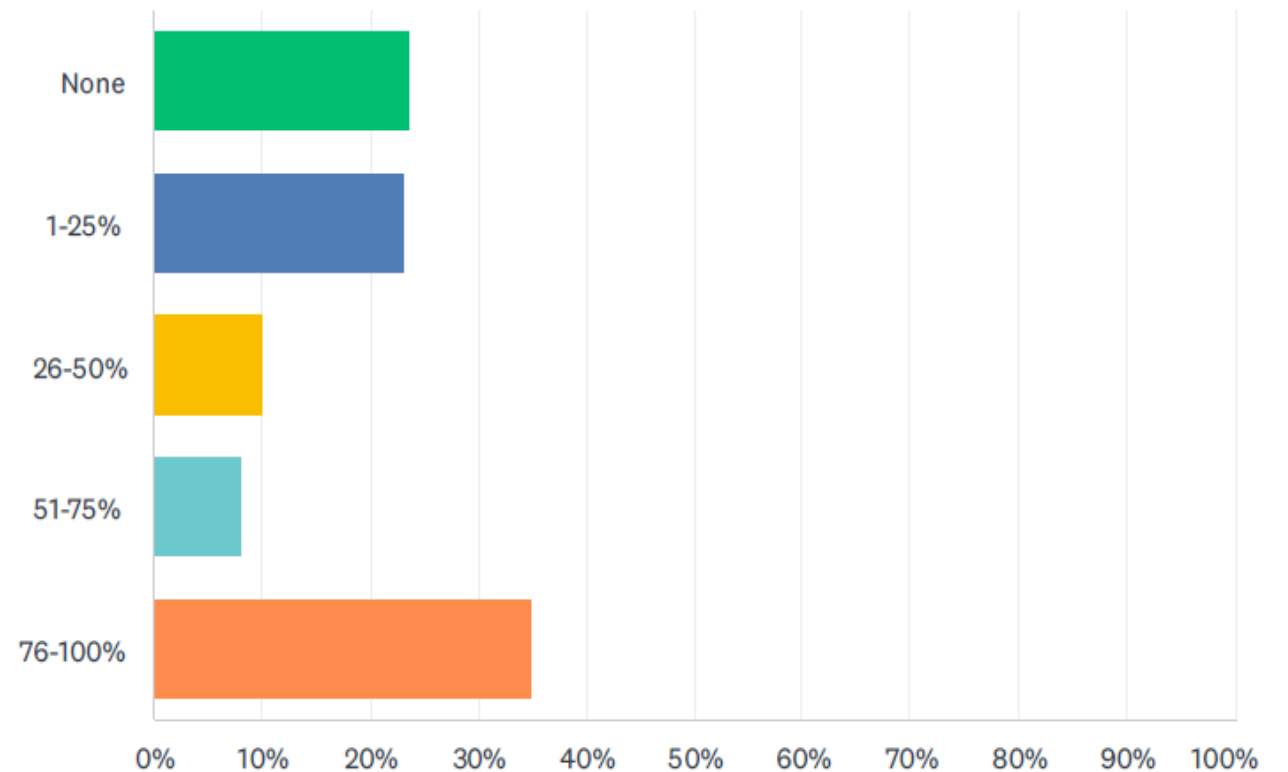


# Written Confirmation after Consultation

## Physician(s)

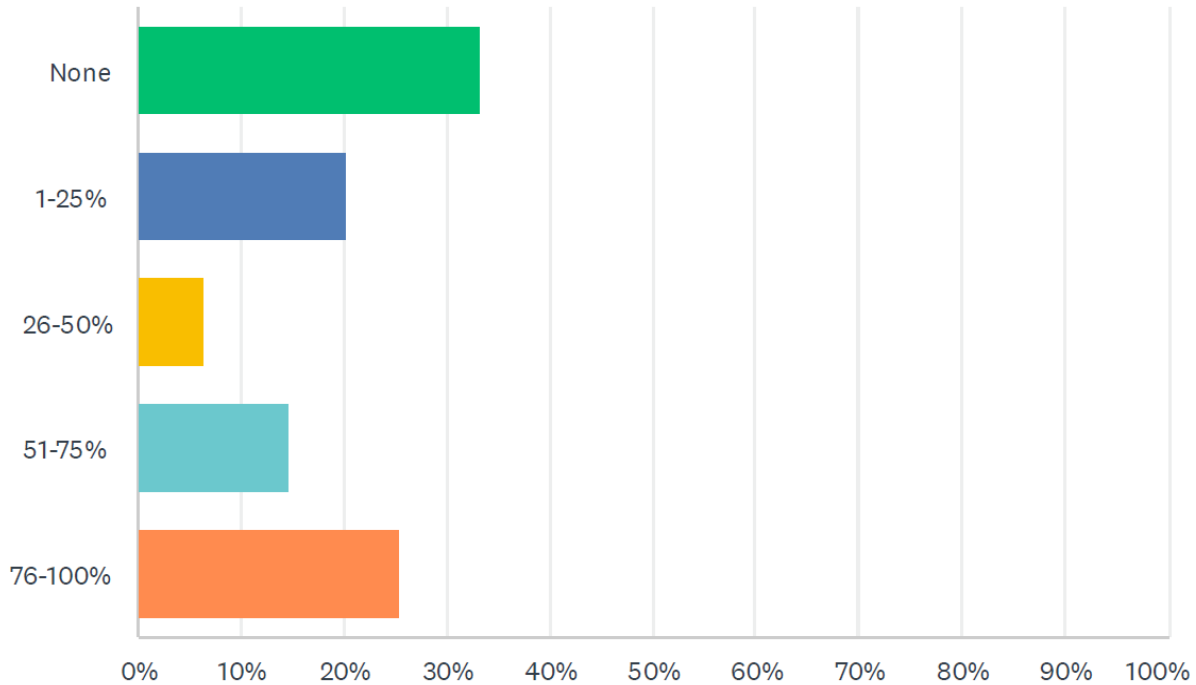


## Allied Health/Education Professionals

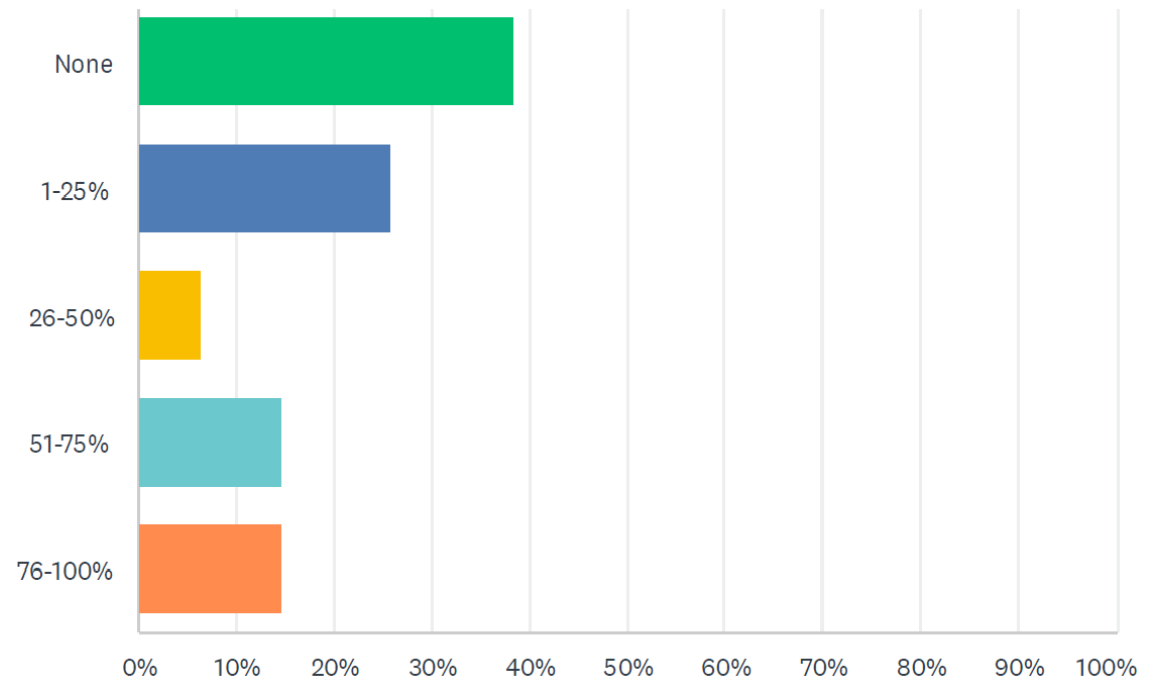


# Physician Review of Entire LCP

## Review/Sign off



## Review Only (w/o Signing off)



## Sources Relied Upon When Direct Physician or Allied Health Input for Recommendations Not Available or Outside Scope of Practice

- Medical records
- Clinical Practice or Standard of Care Guidelines
- Expert testimony
- Literature/published data
- LCPer expertise, education, training, and/or experience



# In your own words, define Charge

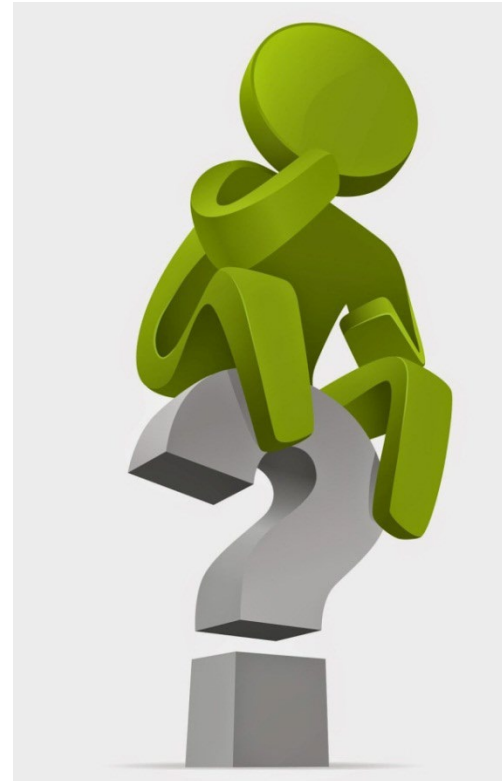
- **No Consensus**
- **Themes**
  - Bill for services/goods
  - Associated cost for an item
  - Cost without discount
- **Concerns...?**
  - What is allowed by physician's guidelines
  - What the insurance company pays





# In your own words, define Cost

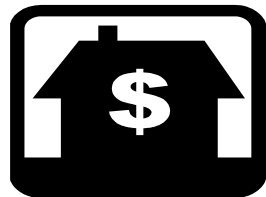
- **No Consensus**
- **Themes**
  - Amount of money needed to purchase a service or item
  - Charge fee for service or item
- **Concerns...?**
  - What is expected to be paid
  - Out of pocket charge
  - Cost for past medical after reductions
  - How much care costs the provider



# Quantifying Costs

A majority of respondents indicate that:

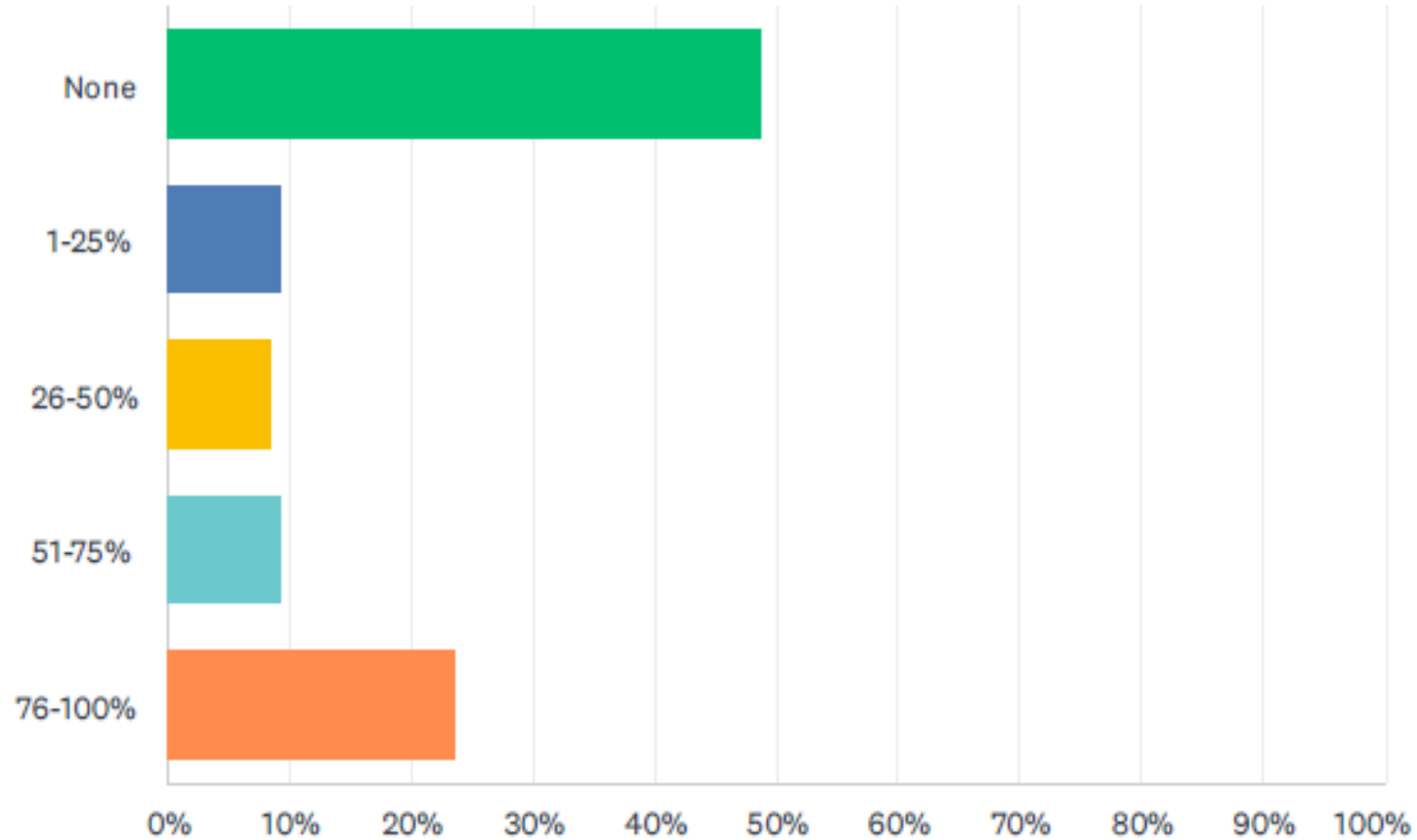
- If difficult to quantify, an annual allowance/allocation for goods/services is included
- Cost of LCP items are not discounted to present value
- Cash prices, billed charges, and established fee schedules are used when developing a LCP; negotiated discount rates are not used
- A specific number of costs quotes are obtained for each item identified in a LCP
- Private/direct hire costs are included when presenting home care options
- Collateral sources are never identified as a mechanism for funding a LCP



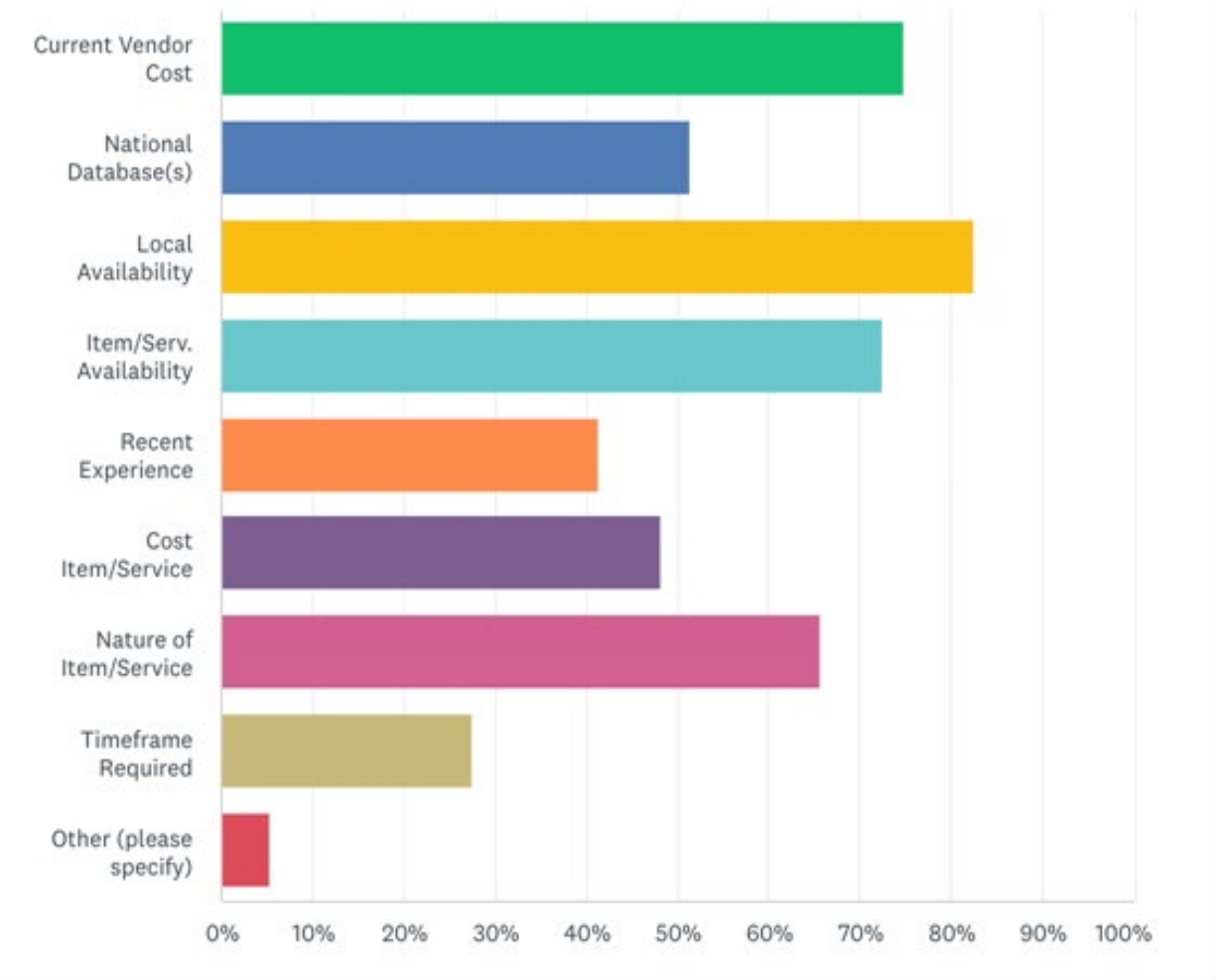
# Include Ancillary Costs



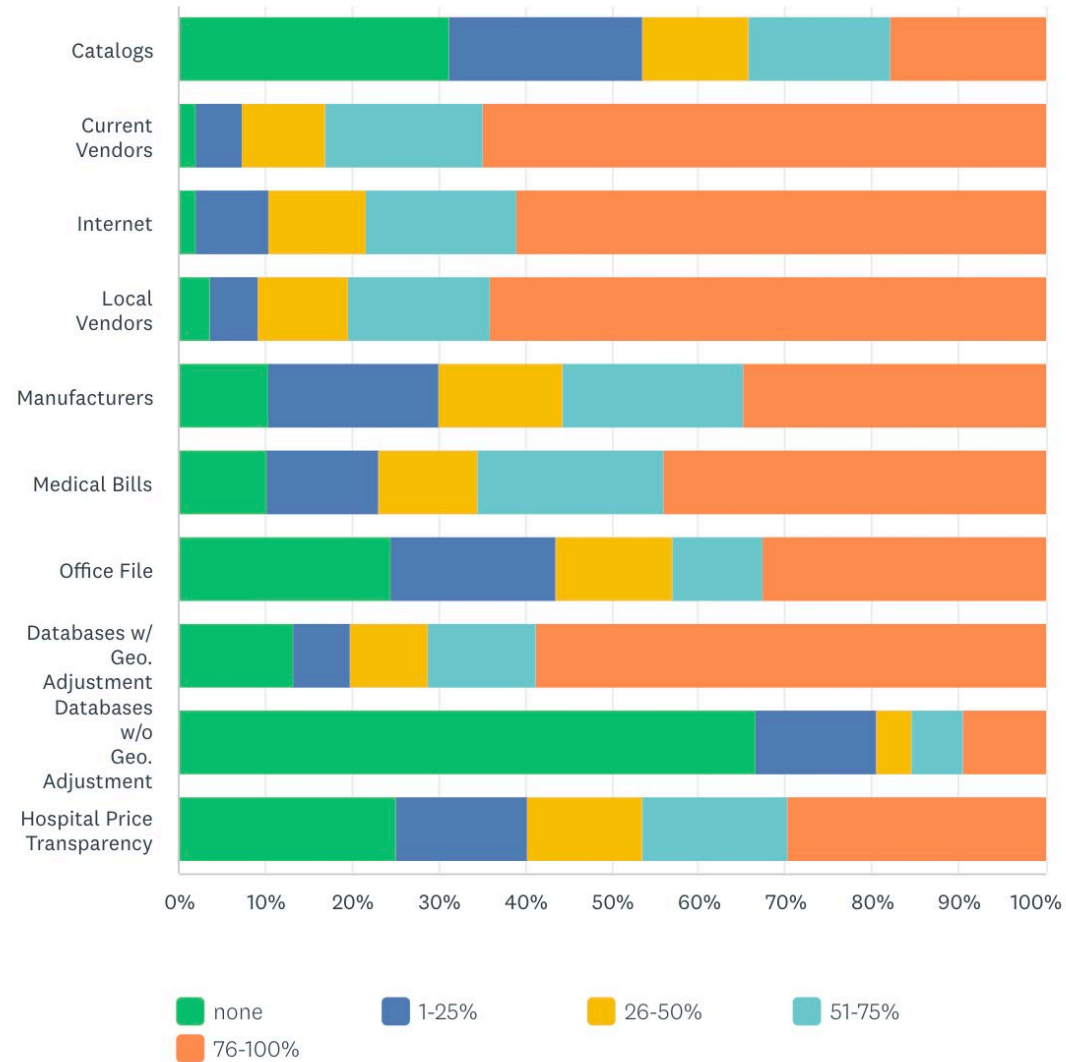
# Include Additional Expense Costs for Live-In 24-hour Care



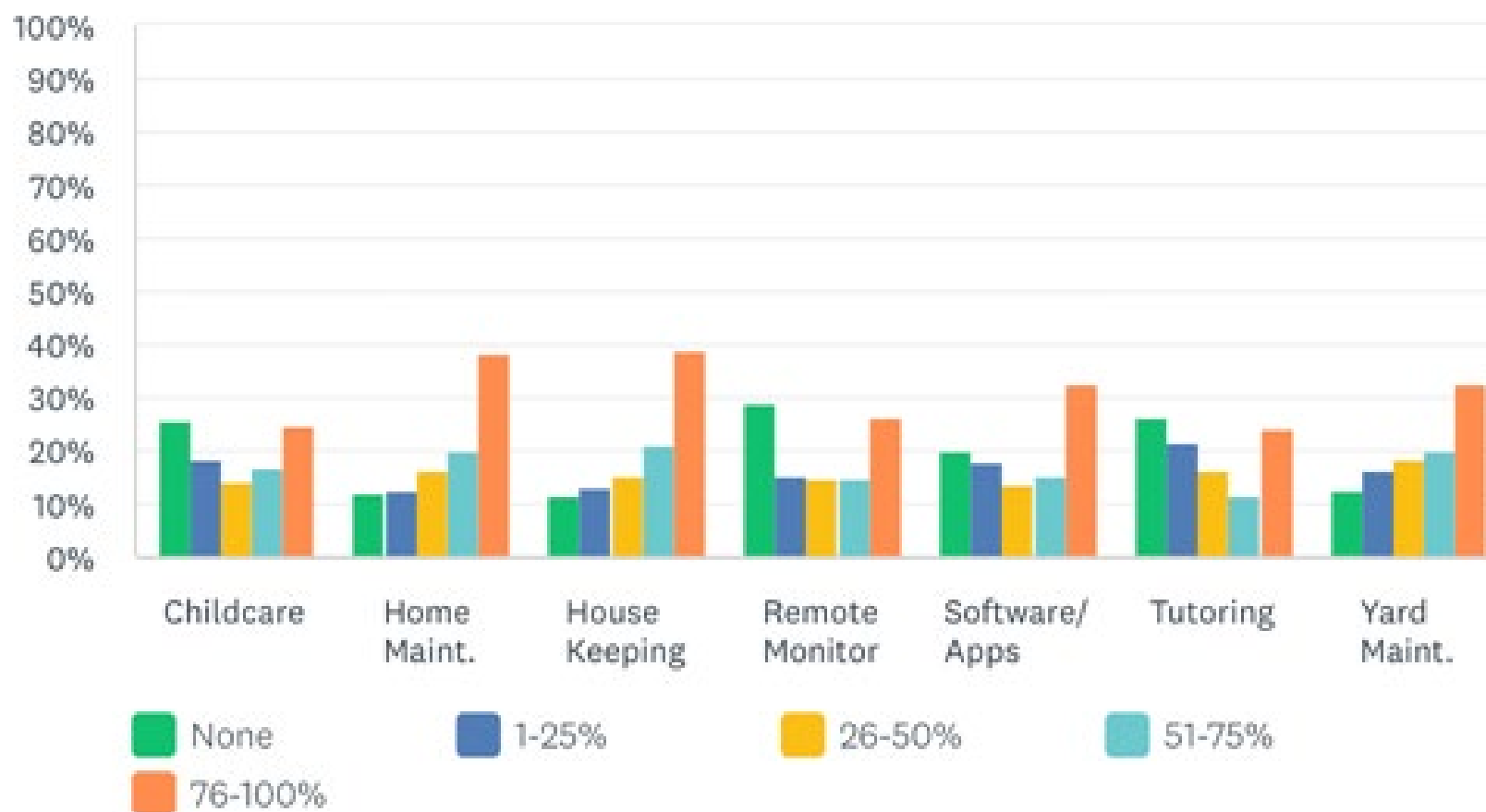
# Factors Affecting Decisions on Number of Cost Quotes



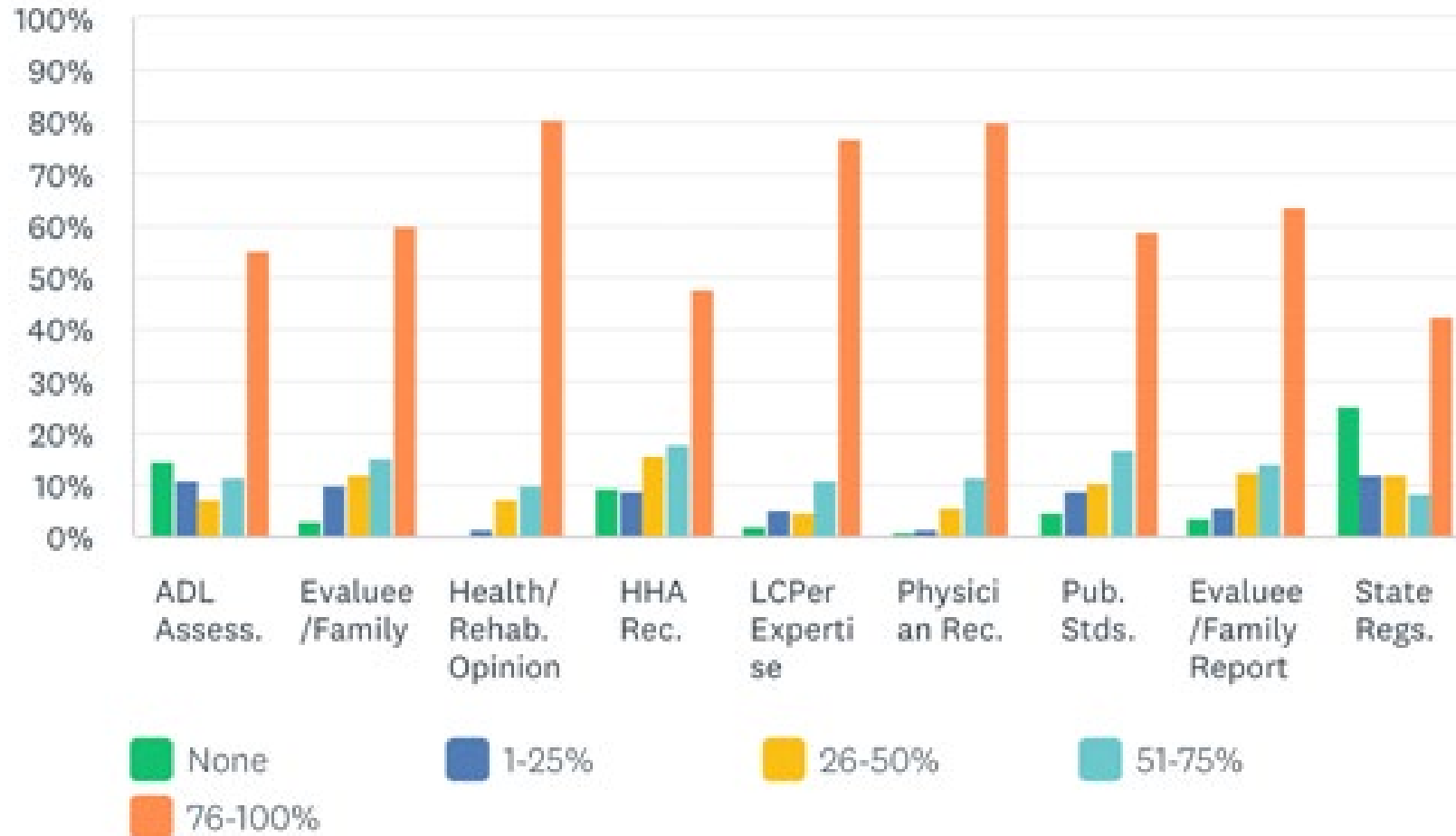
# Resources Used to Obtain Cost Quotes



# Online Resources to Identify Costs



# Sources for Opinions Regarding Home Health Care Needs





# Databases Used to Research Costs

(>51%)

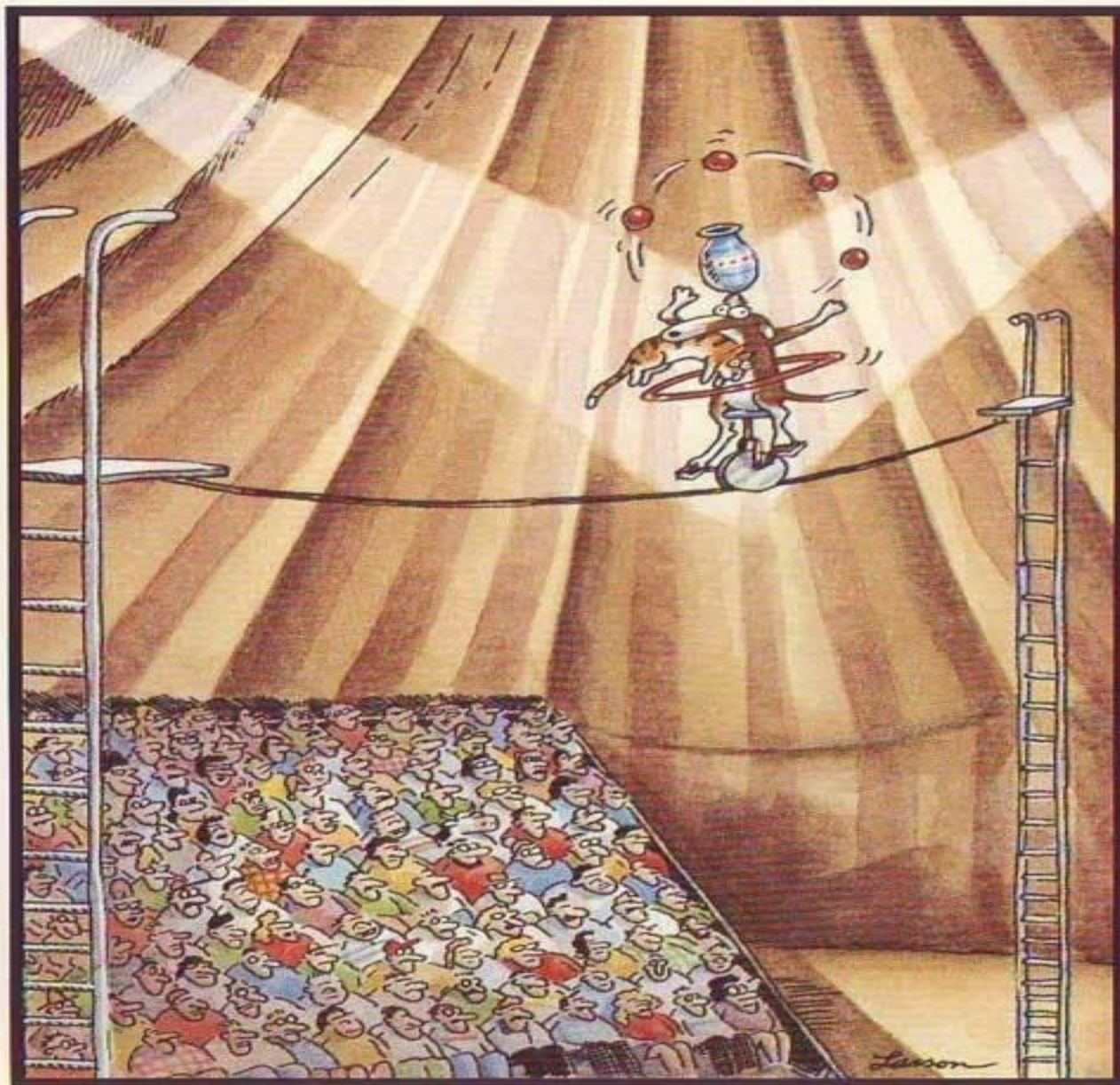
- GoodRx, 73%
- Fair Health, 54%

(31%-50%)

- Am. Hosp. Directory, 48%
- Glenworth Cost of Care, 47%
- Medical Fees in the US, 46%
- Physicians Fee Reference, 43%
- VA Reasonable Charges, 37%
- Hospital Chargemaster, 35%

(<30%)

- Dept. of Labor, 26%
- HCPCS Fee Analyzer, 25%
- Context4 Healthcare, 24%
- Other, 23%
- Physicians Fee/Coding, 22%
- State/Federal/Provincial, 21%
- National Fee Analyzer, 16%
- Red Book, 13%
- HCUP, 12%



High above the hushed crowd, Rex tried to remain focused. Still, he couldn't shake one nagging thought: He was an old dog and this was a new trick.

# Next Steps

- Additional Data Analyses
  - Write-ins ("Other", Rewards, Frustrations)
  - Between Group Differences
    - Geographic location
    - Professional Groups
    - Certification
    - Level of Education
    - Experience (years, sworn testimony)
- Articles
  - Pandemic Survey (March 2023)
  - LCP Survey 2022 (Fall 2023)
    - Overview
    - Age/Retirement
    - Longitudinal Comparisons

