Report of Findings

Part 8

Statewide Survey of NEW YORK STATE RESIDENTS Who Have One or More DISABILITY, Impairment, or Condition That Limits Their Ability to Perform Activities of Daily Living Without Assistance

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Section I
Introduction

Background:

The statewide Survey of Individuals of All Ages with Disabilities is one of seven exploratory studies conducted under the auspices of the New York State *Legal Services Initiative's* four-member Partnership. The purpose of the seven surveys is to gather information about the delivery of civil legal services in New York State, with specific emphasis on three population groups: older adults aged 60 and older; individuals of all ages with physical, mental, developmental, or intellectual disabilities; and the informal, unpaid caregivers of these population groups.

Findings from the exploratory surveys will provide information for the *Initiative's* Partnership and consultative Think Group to: (1) better understand the use of legal assistance by the three population groups, (2) understand the limitations and barriers in the provision of legal services that have an impact on the availability, affordability, and accessibility of legal assistance for these populations, and (3) consider strategies, actions, and policies for addressing these limitations and barriers.

By specifically examining the experiences of the State's population that is characterized by a variety of disabilities, impairments, and chronic illnesses, the intent of the survey of individuals with disabilities is to further clarify the *Initiative's* overall portrait of the status of civil legal assistance in New York State.

Methodology:

The survey's Questionnaire was constructed by the NY State Office for the Aging (NYSOFA) and is a slight modification of the instrument used to conduct the *Initiative's* statewide survey of the State's general population aged 18 and over. The survey was implemented by NYSOFA and was made available in three forms: (1) as a Survey Monkey web-based application for on-line completion, (2) as a Microsoft Word document for printing and manual completion, and (3) as a Microsoft Word document formatted for on-line completion using screen readers. The survey form itself contained a Statement of Assurances for respondents to understand the sponsorship of the survey, intended use of the findings, voluntary nature of the survey, confidentiality of individual respondent data, and assurance that findings would be reported in aggregate form.

Survey sample:

There is no comprehensive statewide list of New York State residents with disabilities; thus, the population universe for the study could not be identified from which a random-selection methodology could be employed to construct a survey sample. As a means of reaching as broad a cross-section of individuals as possible, a letter explaining the *Legal Services Initiative* and the disabilities survey project was emailed to 860 leaders of public and private organizations across the State whose mission is to serve, advocate for, or develop and administer programs for individuals with disabilities, impairments, or chronic illnesses. The letter asked for these organizations' assistance in reaching out to individuals on their client rosters, membership lists, email list servs, and newsletter subscription lists to request that individuals who have "conditions that limit their ability to conduct activities of daily living without assistance from other individuals, equipment, or devices" complete the survey. Survey respondents self-identified themselves as having such a condition and provided a description of their disability, impairment, or chronic condition.

Response rate:
A total of 278 survey responses were received, which included: 255 on-line and manual submissions received in June – August of 2015, and 23 manual submissions received May – July of 2014. Using the "2009-2013 American Community Survey 5-Year Estimates for New York State" (Table S1810, Disability Characteristics), the U. S. Census Bureau estimates that 2,090,781 of the State's civilian noninstitutionalized population has one or more hearing, vision, cognitive, ambulatory, self-care, or independent-living difficulty. For that population, the margin of error for a sample of 278 is +/- 5.9 percentage points with a 95% confidence level. As a number of individual survey questions have less than a 100% response rate, the number of responses included in the analysis is reported for each question.

Presentation of findings:

- Frequencies and cross-tabs are used for reporting and comparing variables, and findings are presented in charts and tables.
- Findings are primarily presented in *proportions* (%) rather than *numbers* in order to provide meaningful comparisons among subsets of variables that vary greatly in number-size.
- Data are primarily presented as statewide findings; several aggregate data are also presented by geographic area (rural, suburban, and urban).
- All comparisons of survey findings with Census Bureau data for New York State use Table S1810, "Disability Characteristics (New York): 2009-2013 American Community Survey 5-Year Estimates," American FactFinder, U. S. Census Bureau, Washington, DC.

Context for reviewing survey findings:

Definition of "disability":
In the Questionnaire, "disability" was defined as "a long-term (lasting six months or more) disability, impairment, or condition that limits your ability to perform routine activities of daily living without assistance from other people, special devices, or equipment."

The Questionnaire's five issue categories:
In the survey Questionnaire, respondents were asked the same series of questions for five categories of issue areas: housing or real estate, family matters, money matters, life planning, and dealing with others. Respondents were asked if they had experienced a <u>serious</u> matter in each category; that is, "a matter that was of great concern and serious enough that the respondent took some special action or wished he could have taken some special action."

Serious issues reported by respondents include both "problems" and "issues that are not problems, but are items the respondent felt ill equipped to handle himself and wanted professional guidance or help."

The following examples of topics related to each issue category were provided in the Questionnaire as a means of stimulating respondents' consideration of issues for each category:

- Housing or Real Estate

  For example, anything related to foreclosure, eviction, mortgage, reverse mortgage, utilities, deed, house sale or purchase, property damage, home repairs, zoning, sidewalks, lease, rent charges, tenants, builder contracts, mobile home, in-home services and care, housing discrimination, nursing home or assisted living, accessibility, landlord, or anything else related to your home, apartment, residence, yard, or other property you own, lease, or rent, etc.

- Family Matters
  For example, anything related to marriage, divorce, foster care, adoption, custody, caregiving, guardianship, family relationships, domestic abuse, Lesbian and Gay issues, health conditions, mental health problems, physical disabilities, developmental disabilities, Alzheimer's care, children's school issues, and anything else related to family interactions and matters, etc.
- Money Matters
  For example, anything related to personal or business finances, any type of insurance policy or payment, credit cards, salary, pensions, social security, banks, any type of taxes, stocks and other investments, debt, bankruptcy, bill collectors, any type of family or business or education loan, employment or job, public benefits, patents and intellectual property, or any other issues related to financial matters.
- Life Planning
  For example, anything related to guardianship, wills, power of attorney, advance directive, estate planning, retirement, savings, future plans or care or education for disabled child, caregiving issues, dementia care for family member, care of elderly parents, death of a spouse, career or educational changes, relocations, long-term care plans, children's college costs, or anything else related to future planning for yourself or someone you are responsible for.
- Dealing with Others
  For example, anything related to harassment, physical or mental or financial abuse or neglect, accessibility or reasonable accommodations in housing or buildings or transportation, any type of discrimination, Lesbian or Gay issues, noisy neighbors, identity theft, fraud, unscrupulous marketers, consumer contracts, landlord/tenant disputes, retail purchases, workplace issues, bullying, or any other issues stemming from dealings with other people, agencies, or institutions.

Representativeness of the survey findings:
Several characteristics of the survey's respondent group support the survey findings' representativeness of the State's disability population, and several characteristics suggest reservations about representativeness.

Three findings supporting representativeness:

***Geographic region and county**:*
The counties comprising the State's ten regional economic development councils are shown in the following table:

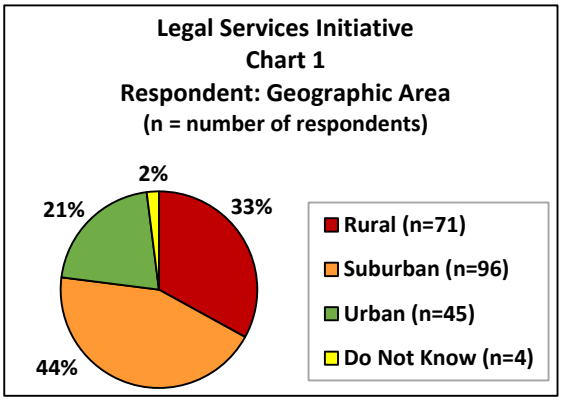
New York State's Ten Regional Economic Development Councils	
Region	**Counties**
1. Western New York	Allegany, Cattaraugus, Chautauqua, Erie, Niagara
2. Finger Lakes	Genesee, Livingston, Monroe, Ontario, Orleans, Seneca, Wayne, Wyoming, Yates
3. Southern Tier	Broome, Chemung, Chenango, Delaware, Schuyler, Steuben, Tioga, Tompkins
4. Central New York	Cayuga, Cortland, Madison, Onondaga, Oswego
5. Mohawk Valley	Fulton, Herkimer, Montgomery, Oneida, Otsego, Schoharie
6. North Country	Clinton, Essex, Franklin, Hamilton, Jefferson, Lewis, St. Lawrence
7. Capital District	Albany, Columbia, Greene, Saratoga, Schenectady, Rensselaer, Warren, Washington
8. Mid-Hudson	Dutchess, Orange, Putnam, Rockland, Sullivan, Ulster, Westchester
9. New York City	Bronx, Kings, New York, Richmond, Queens
10. Long Island	Nassau, Suffolk

208 of the survey's 278 total respondents provided their county of residence. Table 1, which provides the distribution of respondents by New York's geographic regions, shows that the residences of the 208 respondents are spread across all ten regions of the State, coming from 49 counties (79% of the State's 62 counties).

Legal Services Initiative Table 1 Respondent: Region/County of Residence Proportion of Respondents Per Region (n = number of respondents)		
Region	**Respondents' Counties**	**Proportion of 208 Respondents**
Western New York (n=23)	Allegany, Cattaraugus, Erie, Niagara	11%
Fingerlakes (n=15)	Genesee, Monroe, Ontario, Wyoming, Yates	7%
Southern Tier (n=44)	Broome, Chenango, Delaware, Schuyler, Steuben, Tompkins, Tioga,	21%
Central New York (n=13)	Cayuga, Cortland, Onondaga, Oswego	6%
Mohawk Valley (n=11)	Fulton, Herkimer, Montgomery, Oneida, Otsego	5%
North Country (n=15)	Franklin, Hamilton, Jefferson, Livingston, St. Lawrence	7%
Capital District (n=20)	Albany, Greene, Rensselaer, Saratoga, Warren, Washington	10%
Mid-Hudson (n=34)	Dutchess, Orange, Putnam, Rockland, Ulster, Westchester	16%
New York City (n=19)	Bronx, Kings, New York, Queens, Richmond	9%
Long Island (n=14)	Nassau, Suffolk	7%

Type of geographic area:
216 of the 278 respondents self-reported the type of geographic area in which they live.

Chart 1 shows that respondents are spread across rural, suburban, and urban areas of the State.



Type of Disability:
Many people with disabilities have multiple impairments. While survey respondents were asked to describe their "primary disability," the majority choose to report their multiple conditions.

Ten respondents provided no information about their type of disability, and 268 reported one or more of their disabilities. In total, the 268 respondents reported 366 disabilities, which are sorted into eight categories in Table 2.

Table 2 shows that survey respondents are characterized by a very extensive variety of disabilities, impairments, or conditions.

Legal Services Initiative **Table 2** **Respondent: Type of Disability** **Proportion of Total Disabilities Reported** **(n = number of respondents reporting each disability type)**	
Disability Type	**Proportion of 366 Total Disabilities Reported**
Physical Disability (n=85), including: Paraplegia; paralysis; quadriplegia; hereditary spastic paraplegia; wheelchair user; requires a walker; unable to walk; nerve pain in back and legs; systemic muscular-skeletal; neuromuscular pain; poor or no motor skills; spastic; severe back injury; spinal cord Injury; spinal stenosis; degenerative disc; herniated disks; ruptured back discs; mobility problem—due to spinal fusion and nerve damage; chronic pain; chronic neck pain; gross and fine motor impairment; severe sleep apnea; long term frailty—aging; unable to stand or walk for more than a few minutes; osteoarthritis; severe arthritis; rheumatoid arthritis; psoriatic arthritis; neuropathy; myopathy; Spina Bifida; speech problems; speech impediment; unable to care for household tasks; cannot lift the baby; limited energy—inability to drive or walk; birth anomaly with both legs; amputee below the knee; orthopedic; right arm amputated, left arm has no elbow, and fingers do not close; lost right leg above knee; nerve pain and weakness in legs; polio—no use of upper arms or legs; loss of bowel and bladder control; dysphagia—unable to swallow at all; chronic 24/7 facial pain and must use a trach; joint hyper-mobility disorder; partial paralysis of leg—total knee replacement and ankle fusion; extreme fatigue; foot drop; severe balance problem; malformation of hips since birth; nerve impairments; distal arthrogryposis; artificial knees; age-related frailty	23%
Physical Disability—vision and hearing (n=26), including: Blind; blind in left eye; Norrie disease—total blindness; macular degeneration; deaf; hearing loss; profound hearing loss; 1964 rubella epidemic caused hearing loss; need to wear two hearing aids	7%
Physical Disability—CP, MS, MD, and Parkinson's (n=28), including: Parkinson's Disease; end-stage Parkinson's Disease; cerebral palsy; multiple sclerosis; muscular dystrophy; spinal muscular dystrophy; facioscapulohumeral muscular dystrophy	8%
Physical Disability—chronic illness (n=63): Seizures; epileptic seizures; chronic obstructive pulmonary disease; cardio/pulmonary; multiple chemical sensitivities; cardiovascular disease; shortness of breath; cardiomyopathy; cancer; terminal ovarian cancer; breast cancer; disabling hypotension; autoimmune illness; Lyme disease; lupus; pervasive disease disorder; right-side-of-heart failure; fibromyalgia; Kabuki Syndrome; stroke; metabolic stroke; regular oxygen use; necrotic pancreatitis; enterocutaneous fistulas; asthma; mitochondrial disease; sarcopenia; autonomic dysfunction, gastroparesis; chromosomal anomaly; sarcoidosis; hyper noise sensitivity; central nervous system vasculitis; Alstrom Syndrome; dystonia; chromosome deletion; chronic fatigue syndrome; high blood pressure; Fragile X Syndrome; aneurysm; diabetes; tinnitus; osteoporosis; major health issues; Turners Syndrome; chronic blood clotting disorder; gastrointestinal disorders; atrial fibrillation; obesity; morbid obesity	17%
Dementia—aging (n=12); including: Alzheimer's Disease; age-related dementia; Lewy body dementia	3%

Cognitive Impairment (n=25), including: Learning disability; multiple learning disabilities; traumatic brain injury; cognitive deficit/impairment/disability; short term memory loss	7%
Developmental/Intellectual Disability (n=52), including: Developmental delays/impairments; mild mental retardation; moderate mental retardation; severe mental retardation; low IQ due to malnutrition as a child; pervasive developmental disability/disorder; intellectual disability; global developmental delay; Down Syndrome; lack of expressive language and mentally disabled; Rubenstein-Taybi Syndrome	14%
Mental Health (n=75), including: Brain injury; depression; episodic major depression; major clinical depression; post traumatic stress disorder; autism; anxiety; panic disorder; severe panic attacks; bipolar; schizoaffectve disorder; mental Illness; agoraphobia; obsessive compulsive disorder; Tourette's Syndrome; oppositional defiance disorder; attention deficient hyperactivity disorder; psychiatric history; borderline personality disorder; non-verbal; behavioral issues; intermittent explosive disorder; mood disorder; dissociative disorder; Asperger's; seasonal affective disorder; insomnia with nightmare disorder; multiple concussions	20%

Three findings that *may* lessen representativeness:

***Gender**:*
215 respondents reported their gender.
Respondents' gender distribution varies somewhat from estimates reported by the U. S. Census Bureau.

According to the Census Bureau (American FactFinder, Table S1810, "Disability Characteristics: 2009-2013 American Community Survey 5-Year Estimates), 45% of New York's population with disabilities is Male and 55% is Female.

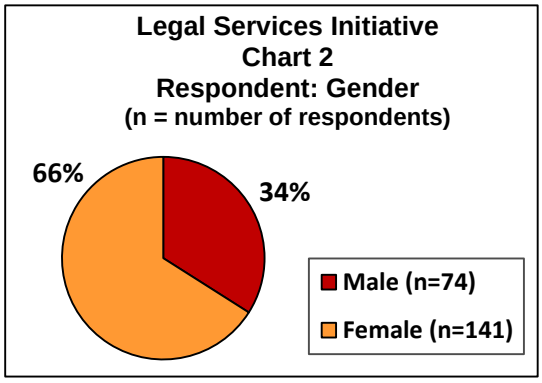


Chart 2 shows that 34% of survey respondents is Male and 66% is Female. The survey's ratio of Male:Female is 1:2, while the Census Bureau's Male:Female ratio is 1:1.2.

However, a substantial number (63, or 23%) of survey respondents provided no gender information, which makes it difficult to judge the extent to which the survey's Male/Female distribution differs from Census Bureau estimates.

***Age**:*
The ages of the 205 respondents who reported their birth year range from 2 – 101 years old, with a median age of 54.

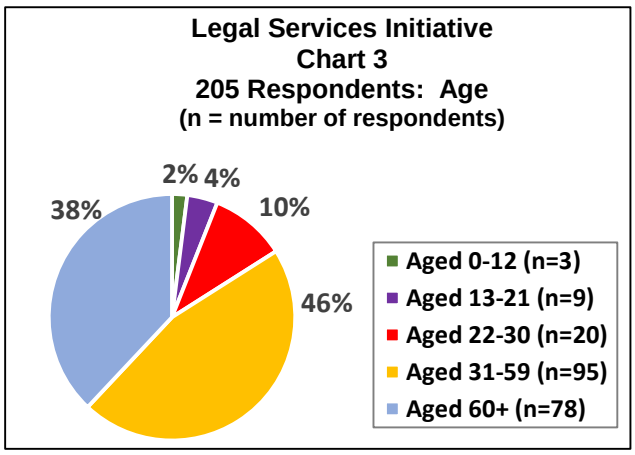
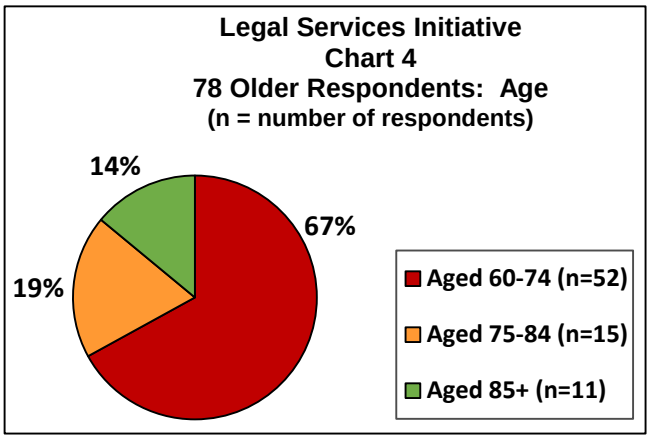


Chart 3 shows that a total of 62% of respondents is aged 0 – 59, and 38% is aged 60 and over. Chart 4 shows that, among the 78 older respondents, a greater proportion (67%) is aged 60-74, compared to a total of 33% who is aged 75 and older.

Compared to Census Bureau estimates, the survey's overall age distribution includes a larger proportion of residents under the age of 60. Census estimates, which use slightly different age categories, report that 58% of New Yorkers aged 0-64 have a disability, and 42% of those aged 65 and older have a disability.

Compared to Census Bureau estimates, New Yorkers aged 0-17 are significantly underrepresented in the survey.

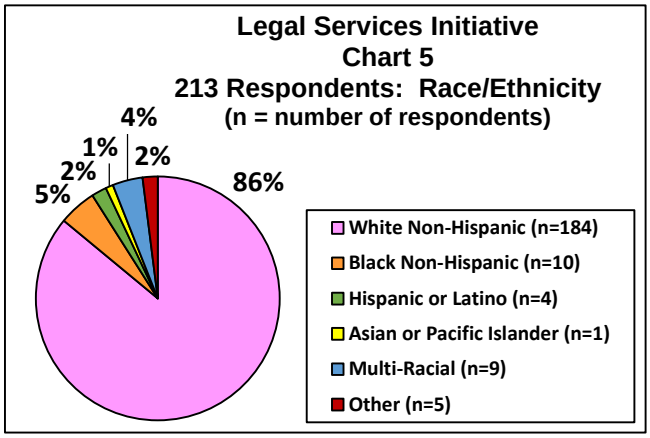
Again, however, as a substantial number of respondents (73, or 26%) did not report their birth year, it is difficult to judge the extent to which the survey's age distribution differs from Census Bureau estimates.



Race/ethnicity:
65 respondents did *not* report their race or ethnicity.

For the 213 who provided information about race or ethnicity, Chart 5 shows that 86% of respondents are White Non-Hispanic, and a total of 14% reported other races/ethnicities.

When compared to Census Bureau estimates for disabilities in New York State (American FactFinder, Table 1810, Disability Characteristics 2009-2013 American Community Survey 5-Year Estimates), all groups except White Non-Hispanic and Multi-Racial are substantially underrepresented in the survey.



Section II
Key Findings

The survey's detailed findings are presented in Section I (Introduction) and Sections III – XII of the Report of Findings. Following are key findings taken from those Sections:

- The survey includes individuals of all ages who self-identify as having a disability, impairment, or condition lasting six months or more.
- A total of 278 survey responses were received, which include 255 on-line and manual submissions received in June – August of 2015 and 23 manual submissions received May – July of 2014.
- New York State's 62 counties are grouped by ten Regional Economic Development Councils. The survey's 278 respondents are located across all ten regions, coming from 49 counties (79% of the State's 62 counties).
- The survey's respondents are spread across rural (33%), suburban (44%), and urban (21%) areas of the State (2% did not report their residence's geographic area).
- Survey respondents are characterized by an extensive variety of disabilities or conditions; 268 respondents described a total of 366 major disabilities or conditions.
- 26% of respondents did not report their birth year. The ages of the remaining 74% of respondents range from 2 – 101. 62% of those respondents are aged 0 – 59, and 38% are aged 60 and older.
- 23% of respondents did not report their race/ethnicity. Among the 213 respondents who did report, 86% are White Non-Hispanic, suggesting that minority residents are underrepresented in the survey.
- The majority (84%) of respondents reside in a variety of conventional living arrangements in the community, and 16% live in various types of certified homes or licensed facilities.
- Respondents' educational levels range across the academic spectrum, from "less than high school graduate" to "four or more years of college."
- The annual household income of 53% of respondents is below $30,000, and 47% have incomes of $30,000 or more, including 12% whose income is $100,000 or more.
- 28% of respondents report that they provide regular caregiving duties for frail, ill, or impaired family members or friends.
- 38% of respondents report that they have "access to affordable transportation when they need it" only sometimes, almost never, or never.
- Respondents were asked if, over the past three to five years, they had experienced a serious issue (serious enough to desire or require assistance from others) in any of five issue categories: housing/real estate, family matters, money matters, life planning, and dealing with others. 82% (228) report having a serious issue in one or more of the five categories, and 18% (50) report having no serious issues in any of the five categories.
- Among the 228 reporting serious issues, the majority (72%) report serious issues in 2 – 5 categories, and 28% report serious issues in one category—for a total of 593 extremely diverse issues.

- The 593 serious issues reported are spread across all five issue categories: housing (138), money matters (135), family matters (123), life planning (106), and dealing with others (91).
- Respondents were more likely to use the assistance of a lawyer, other legal assistance provider, or community agency for issues related to Family Matters (58% of Family Matter issues) and Life Planning (50% of Life Planning issues), compared to Money Matters (42%), Dealing with Others (33%), and Housing (32%).
- Across issue categories, the three primary reasons respondents give for *not* using assistance for their issues are: "they thought they could handle it themselves or with help from family or friends," "they did not know or think the matter was a legal issue," and "they did not think they could afford legal help so did not even consider calling anyone."
- Respondent did use assistance, and the quality of that assistance:
  - *Housing:* For respondents who used assistance to help resolve Housing issues, 59% found the assistance to be only Somewhat Helpful, Not Very Helpful, or Not Helpful At All. Among an extensive list of reasons for their dissatisfaction, the two primary ones are: "they did not spend enough time with me" and "they did not seem to have my best interests in mind."
  - *Family Matters:* For respondents who used assistance to help resolve issues related to Family Matters, 47% rated the assistance as only Somewhat Helpful, Not Very Helpful, or Not Helpful At All. Among their reasons for dissatisfaction, the three primary ones are: "they were not knowledgeable about my particular problem or matter," "they did not seem to have my best interests in mind," and "they did not spend enough time with me."
  - *Money Matters:* For respondents who used assistance to help resolve issues related to Money Matters, 50% rated the assistance as only Somewhat Helpful, Not Very Helpful, or Not Helpful At All. Among their reasons for dissatisfaction, the two primary ones are: "they did not spend enough time with me," and "they were not knowledgeable about my particular problem or matter."
  - *Life Planning:* For respondents who used assistance to help resolve Life Planning issues, 40% rated the assistance as only Somewhat Helpful, Not Very Helpful, or Not Helpful At All. Among their reasons for dissatisfaction, the two primary ones are: "they were not knowledgeable about my particular problem or matter" and "they were not competent."
  - *Dealing with Others:* For respondents who used assistance to help resolve issues related to Dealing with Others, 55% rated the assistance as only Somewhat Helpful, Not Very Helpful, or Not Helpful At All. Among their reasons for dissatisfaction, the two primary ones are: "they did not seem to have my best interests in mind" and "they were not knowledgeable about my particular problem or matter."
- Across the five issue categories, a small proportion (17%) of respondents' issues were brought to court or an administrative hearing for resolution. The issues most likely to be brought to court or a hearing are related to Family Matters.
- An attorney representing the litigant was *not* present for the proceedings in 32% of the cases that were brought to court or a hearing.
- For 20 different topics, respondents were asked to rate their general level of worry as "A Lot," "Some," or "Little or None." Greater proportions of respondents rated their level of worry as "A Lot" for four topics:
  - "My physical or mental health and medications" (44% of respondents).

- "My income, savings, pension, stock market" (42% of respondents).
- "Long-term care and services for myself" (37% of respondents).
- "Government benefits or programs (36% of respondents).

- Among 10 methods for receiving legal information, respondents rated five methods for receiving legal information as "Very Helpful":
  - "A trustworthy referral service that would tell you which lawyer or agency to call to handle your issue, or to tell you which ones serve individuals with limited finances or limited mobility, etc." (72% of respondents).
  - "A telephone hotline where you could call and ask a lawyer questions for free" (63% of respondents).
  - "A website that provides legal information" (60% of respondents).
  - "A legal guidebook for consumers" (46% of respondents).
  - "Community programs on different legal topics" (41% of respondents).
- In Section XII of the disability survey's Report of Findings, extensive optional comments are provided by 50 respondents.

Section III
Respondent—Additional Characteristics

Characteristics of respondents' region/county location, geographic area of residence, type of disability, gender, age, and race/ethnicity are presented in in Tables 1 and 2 and Charts 1-5 in Section I (Introduction). Additional descriptive characteristics are shown below.

Living arrangement: 214 respondents reported on the make-up of their household.

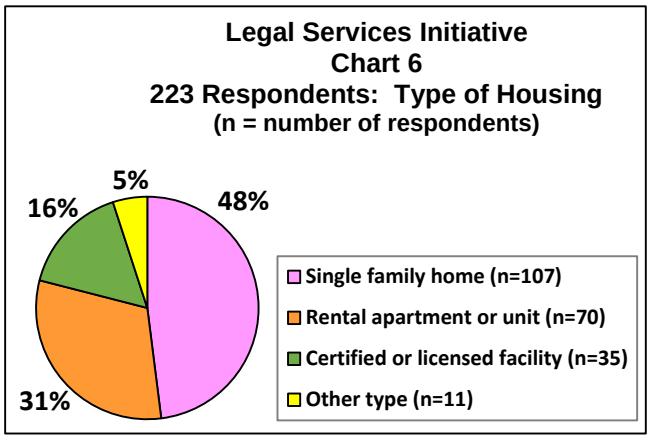
As shown in Table 3, 16% live in certified or licensed residences, over a quarter of respondents (29%) live alone in community housing, and a total of 55% report living in a household with a spouse, one or more adults, or adults and children.

Legal Services Initiative
Table 3
Respondent: Living Arrangement
(n = number of respondents)

Living Arrangement	Proportion of 214 Respondents
Live alone (including 4 who reported living with their pet) (n=63)	29%
Live with spouse (n=8)	4%
Live with spouse and children (n=14)	7%
Live in various type of certified group home or licensed facility (n=34)	16%
Live with various combinations of: with other adults, with parents, with parents and young or adult siblings, with grandparents, with other adult family members or other adults, and with other adults and children (n=95)	44%

Housing type:
223 respondents reported the type of housing in which they live.

Chart 6 shows that almost half (48%) reside in single family homes, 31% live in various types of rental apartment or unit, 16% live in a certified residence or licensed facility; and 5% live in other types of housing, including townhouse, condominium, boarding house, duplex, owner's apartment building, and mobile home.



Marital status:
219 respondents reported their marital status.

Table 4 shows that individuals with disabilities are represented in all eight Marital Status categories.

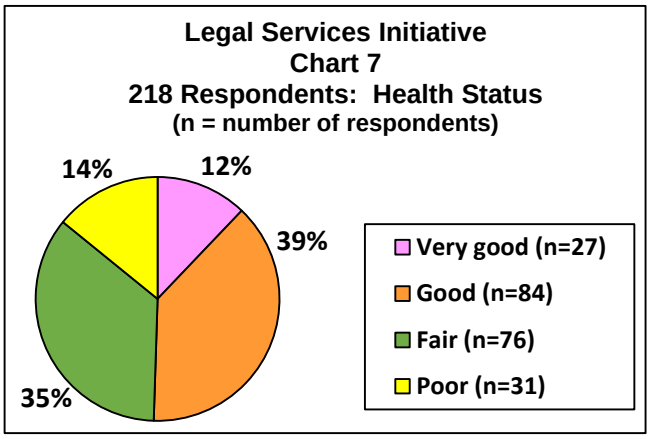
26.5% are married, in a civil or domestic partnership, or in a long-term relationship. 74% are never married, separated, divorced, or widowed.

Legal Services Initiative
Table 4
Respondents: Marital Status
(n = number of respondents)

Marital Status	Proportion of 219 Respondents
Never married (n=85)	39%
Married (n=44)	20%
Separated (n=8)	4%
Divorced (n=32)	15%
Widowed (n=36)	16%
Civil partnership (n=1)	.5%
Domestic partnership (n=5)	2%
Not married, but in long-term relationship (n=8)	4%

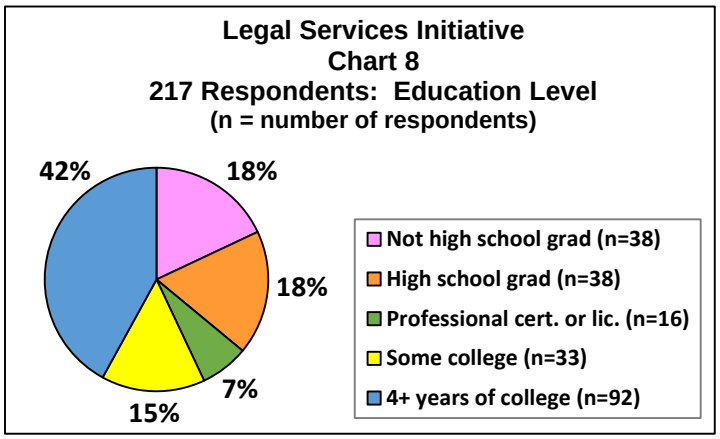
Self-reported health status:
218 respondents reported their health status, and one reported that he "did not know" his health status.

Chart 7 shows that over half of respondents (51%) judge their health to be Very Good or Good. 35% rate their health as Fair, and 14% consider their health to be Poor.



Education:
217 respondents reported their highest level of education.

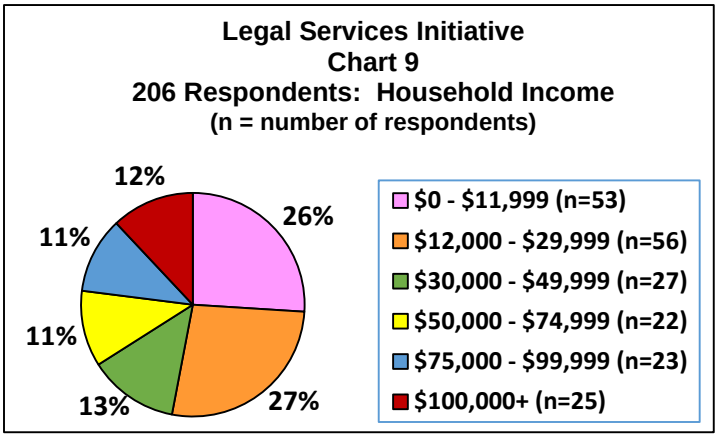
Chart 8 shows that a majority of respondents (64%) completed college or professional certificate classes compared to 36% who had a high school degree or less.



Household income:
206 respondents reported their annual household income.

Chart 9 shows that respondents are spread across all six income categories.

53% have annual household incomes of less than $30,000. 47% have incomes of $30,000 and over, including 12% who have household incomes of $100,000 or more.

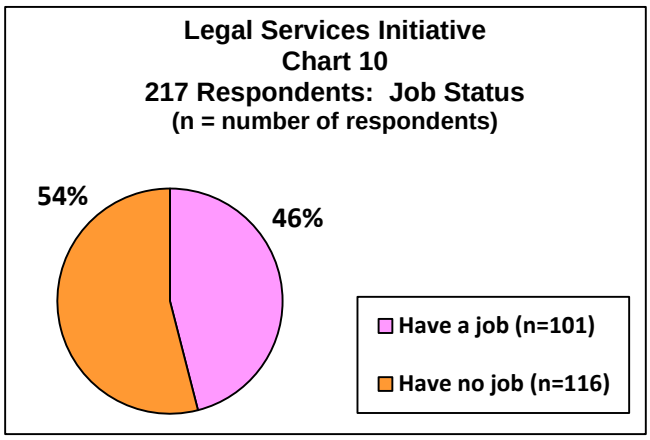


Work status:
217 respondents reported their work status.

Chart 10 shows that 46% have a job.

For the 101 respondents who have a job, 52% work full time and 48% work part time.

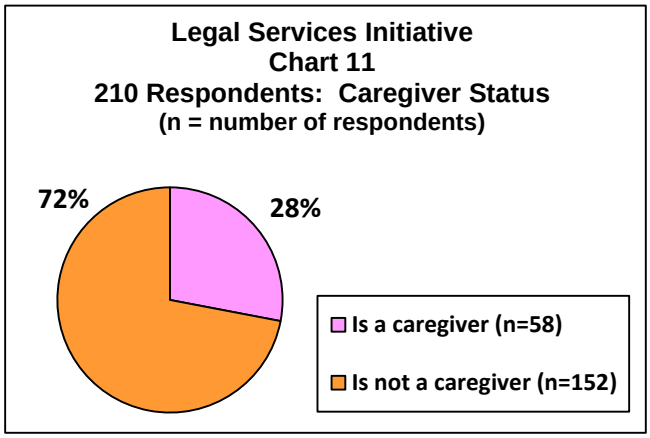
54% of those who are not working reported being retired.



Caregiver status:
210 respondents reported whether they provided informal (unpaid) regular assistance with activities of daily living to a frail, impaired, disabled, or chronically ill family member or friend.

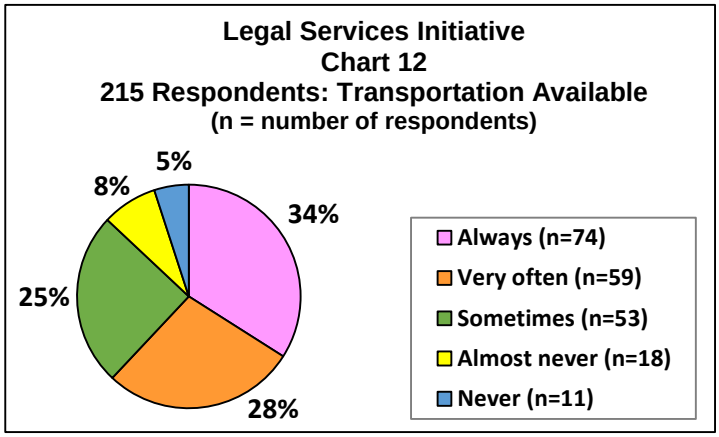
As is shown in Chart 11, 28% of respondents reported providing caregiver assistance.

As a comparison, 31% of respondents in the Legal Services Initiative's survey of New York's general population aged 18 and older reported providing caregiving assistance.

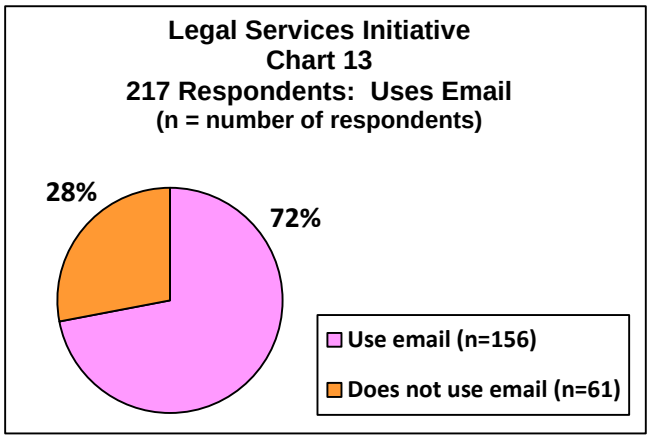


Transportation availability:
215 respondents reported on their "access to affordable transportation when they need it."

Chart 12 shows that 62% of respondents said they had such access always or Very Often. 38% said such access was available Sometimes, Almost Never, or Never.



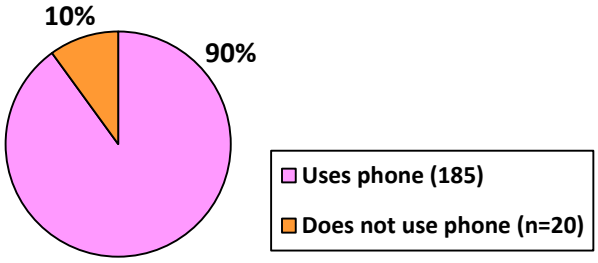
Communication—email:
For the 217 respondents who reported their use of email for communication, Chart 13 shows that 72% indicated that they used email, and 28% said they did not.



Communication—telephone:
205 respondents reported whether they had "access to a working telephone in a location that provides privacy." Among the 205, 96% (or, 197) *have access* to a telephone, and 4% (8) do not.

Chart 14 shows that, among the 205 respondents, 90% *use* the telephone for communication, and 10% do not.

Legal Services Initiative
Chart 14
205 Respondents: Phone Use
(n = number of respondents)



Communication—other technology:
Respondents were asked, "Besides email or the telephone, do you use any other types of technology for communication."

Of the 210 respondents who answered this question, 133 (62%) said no and 76 (38%) said yes.

Table 5 lists the various types of technology used by respondents.

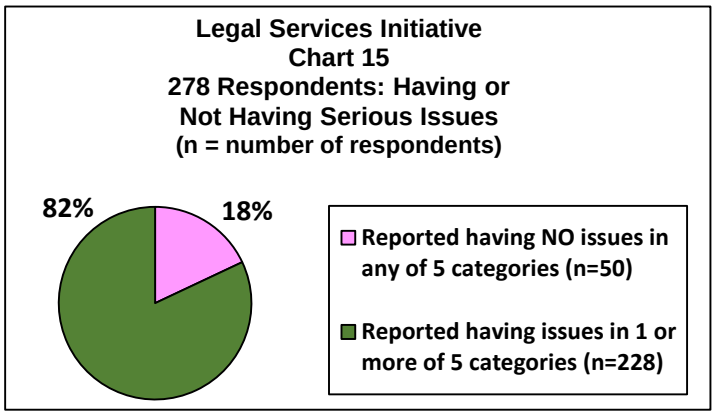
Legal Services Initiative
Table 5
210 Respondents: Uses Technology Other Than Email or Telephone

Computer, including: Tablet, closed captioning, facetime, skype, e-reader, facebook, facebook messaging, Lindedin, internet and various internet platforms, iPad, iPad proloquo and proloquo2go, iPad with communication app, VoiP modes, twitter, other social media
Texting; instant messenger protocols
Short message service (SMS)
Video phone; text-only type phone
Sign language interpreters via videophone
Fax
Ham radio
Lifeline
Braille note
Snail mail; notes or cards; writing letters

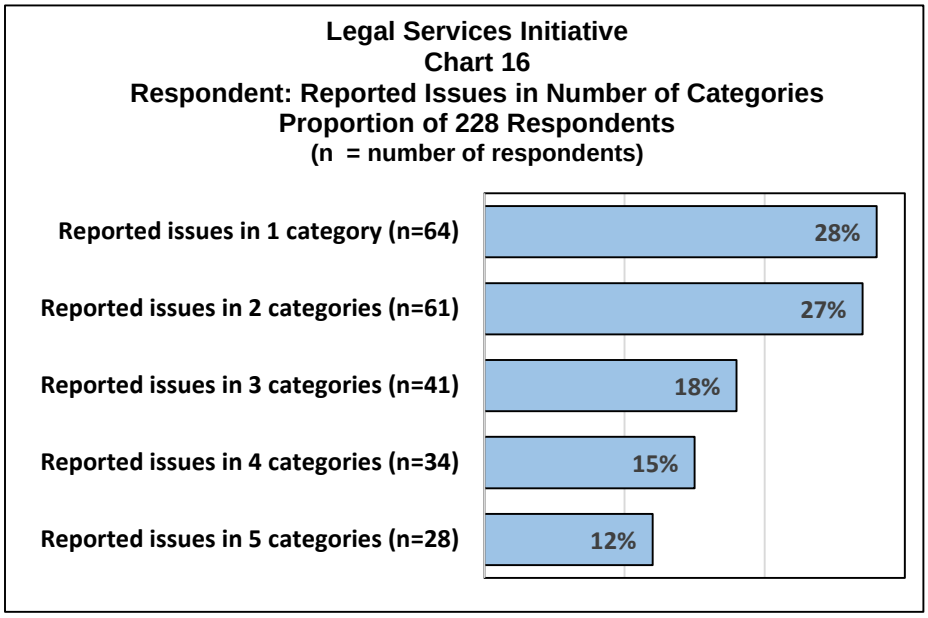
Section IV
Aggregate Findings Across Five Issue Areas

Five issue categories:
Respondents were asked if they "had one or more serious issue or matter in the life areas of: Housing, Family Matters, Money Matters, Life Planning, or Dealing with Others."

Total respondents reporting issues in *any* of five categories:
Among the 278 respondents, Chart 15 shows that 82% (228) reported having a serious issue in one or more of the five issue categories, and 18% (50) reported having no serious issues in any of the five categories.



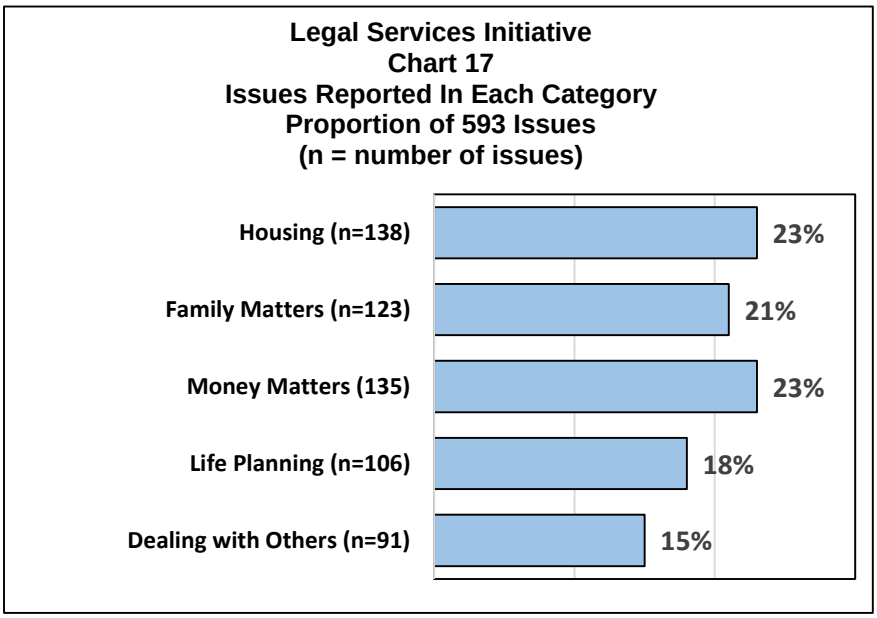
Respondent—reported issues, by number of categories:
Among the 228 respondents who reported having serious issues, Chart 16 shows that greater proportions reported having issues in one category (28%, or 64 respondents) or having issues in two categories (27%, or 61 respondents). In total, 45% of respondents reported having issues in three, four, or five categories.



Total issues reported, by category:
Chart 17 shows that serious issues were reported across all five issue categories.

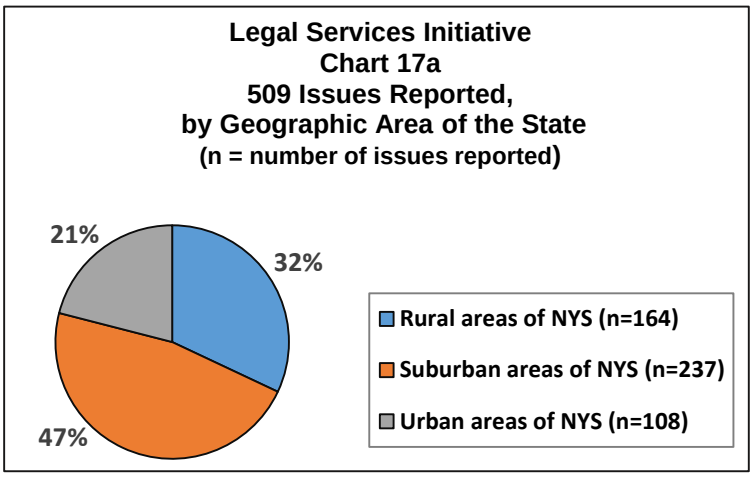
As many respondents reported a serious issue in more than one category, the 228 respondents reported a total of 593 serious issues across the five categories.

As shown in Chart 17, the two categories in which the greatest number of respondents reported an issue are Housing (23%, or 138 issues) and Money Matters (23%, or 135 issues).



Aggregate: Issues reported by geographic area of NY State:
Of the 593 total serious issues reported across the five categories, 509 were reported by respondents who reported *both* their serious issues *and* the geographic area of their residence.

Chart 17a shows that a greater proportion (47%) of serious issues are reported by suburban respondents compared to the proportion of issues reported by Rural (32%) or Urban (21%) respondents.



Proportion of issues, by individual category and geographic area:
Respondents reported a total of 593 serious issues. For 529 of those issues, respondents provided *both* their issues *and* the geographic area of the State in which they lived.

Table 5a shows that across all three types of geographic areas, respondents experienced serious issues in all five issue categories.

Legal Services Initiative Table 5a 529 Issues, by Category and Geographic Area (n = number of issues)			
Issue Category	**Rural Area**	**Suburban Area**	**Urban Area**
Housing (n=107)	31%	48%	21%
Family Matters (n=121)	41%	41%	18%
Money Matters (n=117)	32%	45%	23%
Life Planning (n=97)	36%	45%	19%
Dealing with Others (n=87)	31%	47%	22%

Across all five issue categories, respondents in Suburban areas (41%-48% of issues) and Rural areas (31%-41% of issues) reported greater proportions of issues compared to respondents in Urban areas (18%-23% of issues).

Use of assistance, by individual category:
The 228 respondents who reported 593 issues in one or more category were asked if they used assistance from a lawyer, other legal assistance provider, or community agency in order to get help for their issue in each category.

Table 6 shows that, compared to the other four issue categories, respondents tended to use assistance most for issues related to Family Matters (58% of issues).

In each of the other four categories, respondents reported using assistance to help resolve the matter for 50% or less of the issues.

Legal Services Initiative Table 6 593 Issues: Use of Assistance (n = number of issues reported in each category)		
Issue Category	**Assistance Used for the Serious Issue**	**Assistance Not Used for the Serious Issue**
Housing (n=138)	32%	68%
Family Matters (n=123)	58%	42%
Money Matters (n=135)	42%	58%
Life Planning (n=106)	50%	50%
Dealing with Others (n=91)	33%	67%

Type of assistance used:
Among the respondents who reported using assistance for their serious issues in one or more of the five categories, the types of assistance used most often are:

- A community agency or organization (26% of total times assistance was used).
- An attorney or law firm (25% of total times assistance was used).
- A government agency (13% of total times assistance was used).

Reasons for not using assistance:
Respondents who did *not* use assistance for their serious issues were asked to indicate "why" they did not. Across the five categories, the top five reasons are:

- "You thought you could handle it yourself, or with help from family or friends" (reported by 121 respondents).
- "You did not know or think the matter or problem was a legal issue" (reported by 91 respondents).
- "You didn't think you could afford legal help, so did not consider calling anyone" (reported by 60 respondents).
- "You didn't know where or how to find legal help" (reported by 60 respondents).
- "You could not afford the cost the legal provider said they would charge" (reported by 45 respondents).

Issues brought to court or administrative hearing:
Across all five categories, respondents reported a total of 593 serious issues. For 475 of those issues, respondents reported whether the issues were brought to court or an administrative hearing.

Of the 475 issues, a small proportion (17%, or 82 issues) was brought to court or a hearing and 83% (or 393) was *not* brought to court or a hearing.

Table 7 shows that, compared to the other four categories, a greater proportion (32%) of issues related to Family Matters was brought to court or a hearing.

Legal Services Initiative
Table 7
475 Issues: Brought To Court or Hearing
(n = number of issues reported)

Issue Category	Issue Was Brought to Court or Administrative Hearing	
	Yes	No
Housing (n=119)	11%	89%
Family Matters (n=108)	32%	68%
Money Matters (n=104)	14%	86%
Life Planning (n=82)	9%	91%
Dealing with Others (n=62)	19%	81%

Presence of attorney in the court or hearing when the case is heard:
Of the 82 issues (cases) brought to court or an administrative hearing, respondents reported whether an attorney was present at the proceedings to represent the litigant in 71 cases.

For the 71 cases, proceedings took place *pro se* (without the benefit of counsel) in 23 (or, 32%) of the cases, and a representing attorney was present in 48 (or, 68%) of the cases.

In comparing the five issue categories, Table 8 shows that, compared to the other three categories, litigants appeared *without* the benefit of legal counsel for a greater proportion of cases related to Dealing with Others (55%) and for cases related to Housing (42%).

Legal Services Initiative
Table 8
71 Cases: Presence of Attorney in Court or Hearing Room When the Case Was Heard
(n = number of cases)

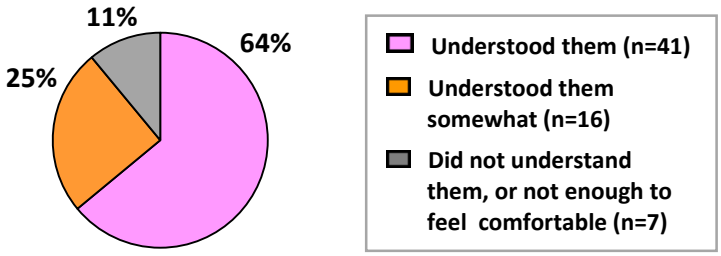
Issue Category	Attorney Was Present in the Court or Hearing When the Litigant's Case Was Heard	
	Yes	No
Housing (n=12)	58%	42%
Family Matters (n=30)	80%	20%
Money Matters (n=12)	67%	33%
Life Planning (n=6)	67%	33%
Dealing with Others (n=11)	45%	55%

Litigants were most likely to be represented by counsel (80% of cases) in issues related to Family Matters

Respondent's Understanding of Court/Hearing Procedures and Steps:
64 respondents answered the question, "If you were in the court or hearing room when your case was heard, how well did you understand the steps you needed to take and the procedures you needed to go through to get to the place where your case was being heard"?

Chart 18 shows that, across the five categories, a majority (64%) of respondents "Understood" the court/hearing procedures and steps, but over a third (36%) understood the steps and procedures only "Somewhat," "Not Enough to Feel Comfortable," or "Did Not Understand Them at all."

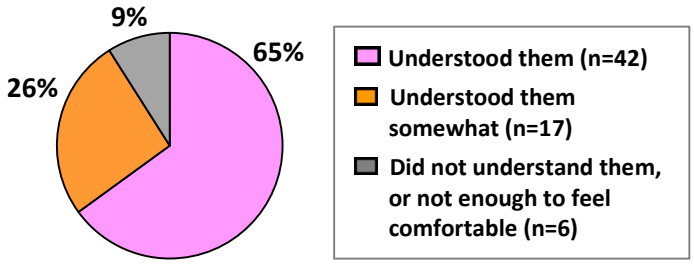
Legal Services Initiative
Chart 18
64 Respondents: Understanding Court or Hearing Room Procedures
(n = number of respondents)



Respondent's Understanding of the Legal Discussion, Explanations, and Judge's Decision:
65 respondents answered the question, "If you were in the court or hearing room when your case was heard, how well did you understand the judge's and attorney's discussion, their words and explanations, and the judge's decision about your case"?

Chart 19 shows that 64% of respondents "Understood" the discussion and decision, but over a third (35%) understood the discussion and decision only "Somewhat," "Not Enough to Feel Comfortable," or "Did Not Understand Them at all."

Legal Services Initiative
Chart 19
65 Respondents: Understanding Judge and Attorney Discussion and Decision
(n = number of respondents)



Section V
Issue Category—Housing

Housing—type of issue reported:
138 respondents reported having serious issues related to Housing. 126 of those respondents described a total of 142 very diverse housing-related matters, which are sorted into 12 groups in Table 9.

The greatest number (47) of matters reported are related to affordability (including 33 for general affordability and 14 for eviction, foreclosure, and homeless) and related to accessibility (25).

Legal Services Initiative
Table 9
Respondent: Type of Housing Issues Reported
(n = number of respondents describing the issue)

Affordability (n=33), including:
Housing is not affordable. Finding suitable housing at affordable prices. Inadequate affordable housing. Slim pickings; nothing affordable; nothing designed for the disabled. Unable to find affordable housing. Unable to pay bills. Had to file for bankruptcy. Utilities.

Rent is too high. ARC used to pay my entire rent, but now they have decreased the amount they will subsidize by a substantial amount ($300)—my landlords are my parents, so they won't evict me, but other landlords would. Have to live with parents because no money to move out—unpleasant situation for all. Parents are elderly and I still live with them and still have a LOT of student loan debt. Still living with parents, and I can't get a job to move out. I have OPWDD waiver services with self-direction, but I

have been unable to begin the housing supports that are in my budget because of problems with the Medicaid Service Coordination provider—I live with an aging parent and would lose housing if my parent passes away. Cut off from Department of Social Services benefits. Scrie/Drie (Senior Citizen Rent Increase Exemption/Disability Rent Increase Exemption) disparity increased rent with lease and MCI, so increase exceeds my Social Security Disability Insurance. In a small town, rentals are scarce and very expensive—almost always beyond the entire Supplemental Security Income monthly check. I applied for New York City Housing Authority in September 2011, but still have not received any response. I filled out all the necessary paper work for public housing when I was discharged from the hospital after 10 months of being there—I received a letter saying I was not a priority for help with housing unless I was in the witness protection program or had AIDS or was a victim of domestic violence—have no arms to do life's daily routines or be able to work, but that was not a good enough reason for help. Disability made it difficult to perform "normal" tasks or fulfill responsibilities—I could not earn money, nor pay a rent. Unable to afford safe, clean housing in Westchester on my disability income. Hard to find rooms I can afford. Late rent. Making timely application to a 202 housing project and being selected for a limited number of slots post-construction.

Closing costs for mortgage were unaffordable. Couldn't afford mortgage payment, even with three family members contributing who were all on disability due to the same illness. Two mortgages on my home. Modification of mortgage due to outrageous out-of-pocket medical—almost went into foreclosure. Mortgage. No money to fix my house. Property taxes on five-acre property with mobile home increased from $500 to $2400 over 2 years; three daughters are co-owners and were not able/willing to pay the taxes; needed to set up an installment plan and borrow money to pay current tax bill; communication with the town clerk and county tax service was difficult; had to arrange a ride to Binghamton for invalid mother to set up installments as they required the owner's presence.

Eviction / Foreclosure / Homeless (n=14), including:

Eviction. Threat of Eviction. Eviction and homeless. Due to being in the hospital and having to go on disability—fell behind in rent, got evicted, and was homeless for five months. No legal services would give me any assistance at all—I ended up homeless for 3 months with a 16-year-old diabetic cat. In the case of a previous illegal eviction years ago, where I had lived for 20 years, new owner has also enacted illegal eviction. Wrongfully accused of causing damage, given notice, and had to move. Had nowhere to live past August 31, 2015; had been living in temporary accommodation for at least a year up until May 26 this year. Foreclosure. Section 8 almost discontinued due to outbreaks of noise and disturbances due to mental illness.

Accessibility (n=25), including**:**

Accessibility in and to my house. My bedroom, where I prefer it to be, and ADA-compliant bathroom are on second floor; also, some friends of similar age cannot visit because of the stairs. Decline in ability to access home; unable to pay for handicap accessibility changes to my home; unable to comply with zoning laws to build access. Difficulty with steps; handicap bars needed, and toilets need replacement. Frequent too-loud fire alarms that trigger epileptic seizures. I have to have a space that is on one level; it must be quiet, without exposure to chemicals like cigarette smoke, exhaust fumes, and fragrances, and it must be warm. I have mobility problems.

Where I live is not wheelchair-accessible. Numerous ADA violations within my unit and throughout the development. The apartment is not at all accessible. The sidewalk and driveway are in disrepair—it is unsafe for me. Steep stairs.

Cannot find accessible housing, and real estate professionals have no idea what accessibility or visitability means. Unable to find affordable, accessible housing. My rent continues to rise, but I am unable to find an accessible alternative. Difficulty finding a home that had a bath on the first floor and that the banks would give me a VA mortgage on. Difficulty finding affordable, accessible rental property. Finding an affordable apartment that was accessible and had parking available. Finding either wheelchair-accessible housing or finding rentals that allow for some modifications—most require that I pay for them and, then, pay again to restore the rental to its previous condition when I move out. Finding wheelchair-accessible property for rent that is NOT for persons with limited income. Convincing a private owner of an apartment building to allow me to install a roll-in shower at my own expense—

convincing the same owner, after residing in the apartment complex for a number of years, to institute evacuation practices and protocols in coordination with first responders. Home modifications. Finding an affordable handicapped-accessible apartment in Ithaca.

Supportive Services and Care (n=14), including:
Being able to find a residence that provided 24-hour support. Became isolated and depressed while living in own apartment—extremely poor hygiene, stopped eating, and had to be hospitalized. I am a quadriplegic—I need assistance with virtually everything. In-home services regarding need for 24-hour care was unavailable due to lack of financial resources—in Albany County. Keeping up with yard, house maintenance, garbage disposal. Live with parents—not enough supported programs that include housing. Living in home that is owned in partnership with two other men with intellectual or developmental disabilities, but cannot get maintenance support, despite the fact that all three could be in an Intermediate Care Facility costing much more. My mother kept falling in her apartment because of her balance problem—she finally required 24/7 care. Problem with keeping up with housework—have no relatives or friends who are willing or able to help. Receiving Community Habilitation services for son in supported apartment. When parents are gone, where will I live? There is no group home availability. Affordable and reliable care to allow me to stay in my own home. Caregiving parent died and sisters had to take over but had jobs; needed to get funding for caring for this person in order to stay home and take care of her; moved her into one sister's home, and care is now shared between two sisters—one during the week and the other on the weekends. Fortunately my son lives in a group home—we are lucky.

Family Dynamics (n=5), including:
Family member arrested for serious assault. Kicked out of my parents' house. My daughter lived with me and was my main caregiver; there was an incident of physical abuse between my daughter and son when I was in the hospital for emergency surgery; he told me he would do everything she did when she moved out---but he did nothing. My son was unable to be managed at home and was admitted to the Children's Psychiatric Center. Purchased a home through government loan program and other supports with a family member, but could not continue commitment because of our failing relationship.

Estate Planning (n=3), including:
My parents passed away; I have a Supplemental Needs Trust—could their house have been included in my trust for my use as my home? When/how to move to a nursing home and retain our home for a community spouse. Estate planning for home purchase—we got legal help, but still felt very confused and mostly on our own.

Harassment / Discrimination (n=11), including:
Cannot say anything without threat of eviction—another tenant seems to take over here and does not allow others to participate in the gardening and activities, storage, etc. Supervisors do not listen to my issues or concerns—not feeling safe.

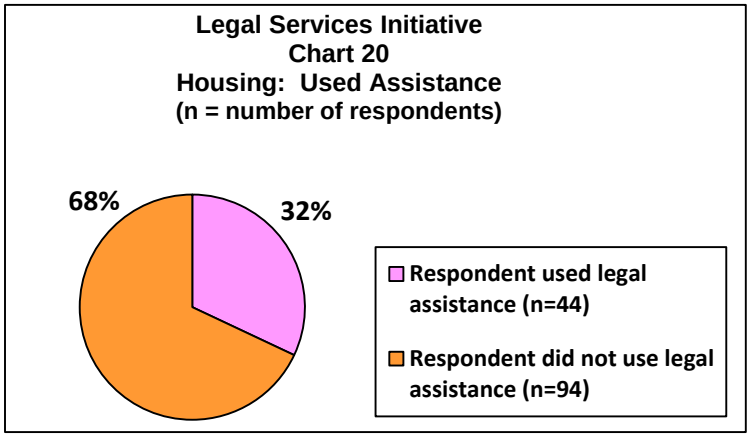
Housing discrimination. Lease discrimination. Discrimination by potential landlords once they learned I was disabled and on Social Security Disability Insurance. I have a guide dog and was denied on several occasions when attempting to secure a new apartment. I have Section 8; when we had to find a new apartment, I searched diligently for 10 months, and not one landlord would accept Section 8 (even with letters of recommendation from my pastor and my current landlord)—many of the landlords had no problem with my three cats, but none of them wanted anything to do with Section 8. Issue with emotional-support animal. Needed one-floor-plan house—some landlords would not rent to persons with disabilities. Owner refused to rent to me because of my son's disability. Unable to have service dog.

Landlord Interactions (n=6), including:
Landlord problems—utilities failed due to landlord's failure to repair floor after he was made aware of the problem. Landlord wouldn't fix anything and said I would have to pay for them on top of rent. Problem with large pet in apartment. Absentee landlord. Staffing and management of the house my son lives in.

Total lack of any clout in landlord/tenant situations regarding repairs, or the provision of necessary insulation to alleviate high utility bills; being treated as though a tenant was nothing but property, even though the tenant always paid rent in full and on time and did almost all maintenance, was clean, quiet, drug/alcohol-free, and non smoker.
Condition of Home, Apartment, or Property (n=10), including: Damage to home due to defective appliance. Person did damage in my house. Heating furnace. Heating issues. Home repairs. Building did not have a fire escape, and long-outstanding building violations that affected the tenants and the condition of the building. Leaky roof and mold. My home fell into disrepair, causing an inability to live in the residence. Problems getting things repaired. We discovered that our house was not at all insulated and were having rain coming in through walls, as well as water pipes that were freezing in the winter as they were nowhere near an outside wall.
Issues Due to Storms (n=4), including**:** Lost our two-bedroom cottage and everything we owned due to Frankenstorm Sandy; we had a difficult time finding a new permanent home—home owners and realtors didn't want anyone on Social Security Disability, Supplemental Security Income, or the Temporary Disaster Assistance Program) and we are still living in a one-bedroom apartment on the second floor that was supposed to only be a temporary situation. Damage from winter storm, and the insurance companies refuse to pay—unable to pay high heating costs. I did not have a problem, but we were able to get housing during the window where there was Options for People Through Service funding—this no longer exists and I understand that if we were looking now there would be NO options. Lost our home due to Hurricane Sandy.
Interactions with Contractors and Others (n=6), including: Difficulty contacting and hiring contractors for home maintenance and repair because can't speak on phone clearly. Heating/Ventilation/Air Conditioning issues, incomplete service, unsatisfied. Remodeling work that was not done properly. Insurance company demanded I get my trees trimmed. While trying to sell house, had water damage in winter—insurance carrier dropped coverage after that. Sued by neighbor.
Regulatory Environment (n=11), including: I do not have title to my home. I had 30 days to find a new home for my mother and get her moved. I needed advice on selling my home, and no one locally would help me. I will never be able to live alone. It took 12 years to establish my son's group home—between HUD, the city of Mt. Vernon, and various other issues. Senior housing's confusing financial rules. Major roadblocks and delays encountered over an eight-year period related to moving from parental home to community supported living. Not happy with where I live. Second mortgage papers not completed correctly. Process to get me out of jail so I could live in the Special Housing Unit. Unable to obtain monies spent by agency for housing/care/medical/specialized services/medications—little to no choice in above—lack of transparency.

Housing—used assistance:
Respondents were asked if they used the services of a lawyer, other legal assistance provider, or community agency in order to get help with the most serious housing-related issue they had.

Chart 20 shows that, among the 138 respondents reporting serious issues related to Housing, 32% (or, 44) used some type of assistance and 68% (or 94) did not use assistance.



Housing—why did *not* use legal assistance:
Table 10 shows that, among the 94 who did *not* use legal assistance for their most serious housing issue, 90 reported 151 reasons why they did not. The most prevalent reason is that the respondent "thought he could handle it himself, or with help from family or friends" (24% of reasons).

Legal Services Initiative
Table 10
Housing: 151 Reasons Why Respondents Did Not Use Legal Assistance for Serious Issue
(n = number of respondents reporting the reason)

Reason	Proportion of 151 Total Reported Reasons
Thought you could handle it yourself, or with help from family or friends (n=36)	24%
Did not know or think the matter was a legal issue (n=20)	13%
Did not think you could afford legal help, so did not consider calling anyone (n=17)	11%
Did not know where or how to find legal help (n=13)	9%
Could not afford the cost the legal provider said they would charge (n=12)	8%
They said they did not handle your type of problem (n=9)	6%
Called someone, but they never called you back (n=7)	5%
Spoke to someone, but they said you did not have a case (n=6)	4%
Waiting list for getting legal help was too long (n=5)	3%
They refused to take your case (n=5)	3%
Had no way to get to the lawyer's or agency's office (n=3)	2%
They wanted to provide help over the telephone, but that would not work well enough for you (n=1)	1%
You were concerned that language or communication problems would limit your discussions with the lawyer (n=1)	1%
They would not come to where you lived (n=0)	0%
Other reasons (n=16)	10%

Housing—type of assistance provider used:
Of the 138 respondents reporting a serious issue related to Housing, 94 (68%) used no type of assistance to help resolve their Housing issue, and 44 (32%) reported using one or multiple types of assistance, for a total of 92 types used.

Table 11 shows that a "Community Agency or Organization" (26%) and a "Lawyer or Law Firm" (20%) were the types of assistance used most often for Housing issues.

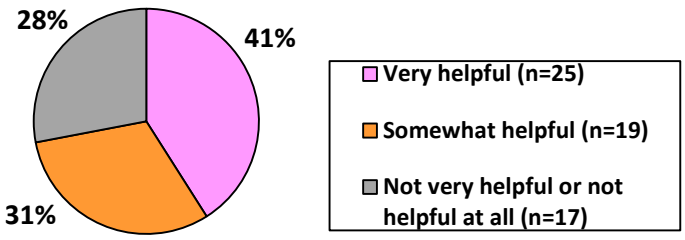
Legal Services Initiative
Table 11
Housing—Type of Assistance Provider Used
(n = number of respondents using provider type)

Type of Assistance	Proportion of 92 Total Types Used
Community agency or organization (n=24)	26%
Lawyer or law firm (n=18)	20%
Local Independent Living Center or Association for Retarded Citizens (n=14)	15%
State or local government agency (n=12)	13%
Local Office for the Aging (n=9)	10%
Legal Aid Society or other free legal clinic (n=7)	8%
Mediation service (n=2)	2%
Ombudsman (n=0)	0
Police (n=0)	0
Other type (n=6), including: contractor, financial advisor, family, realtor and mortgage broker, and internet	6%

Housing—quality of the assistance used, or contacted but not used:
For housing issues, 61 respondents rated the overall assistance they used or tried to use but were unsuccessful.

Chart 21 shows that 41% of respondents found the assistance they used for Housing to be "Very Helpful," and 59% found the assistance they used or attempted to use only "Somewhat Helpful," "Not Very Helpful," or "Not Helpful at All."

Legal Services Initiative
Chart 21
Housing:
Housing: Quality of Assistance Used
(n = number of respondents)



Housing—reason for dissatisfaction with quality of assistance:
For Housing issues, 35 respondents reported 46 reasons or comments about why the assistance they received—or attempted unsuccessfully to use—was only "Somewhat Helpful," "Not Very Helpful," or "Not Helpful at All."

Table 12 shows that the most prevalent reasons are: "they did not spend enough time with me" (15% of all reasons) and "they did not seem to have my best interests in mind" (15%).

Legal Services Initiative
Table 12
Housing—Reasons for Dissatisfaction with Quality of Assistance
(n = number of respondents reporting the reason)

Reason for Dissatisfaction	Proportion of 46 reasons
They did not spend enough time with me (n=7)	15%
They did not seem to have my best interests in mind (n=7)	15%
They were not knowledgeable about my particular problem or matter (n=4)	9%
They were not competent (n=3)	7%
They were never available when I needed them (n=3)	7%
The help they provided was not worth the cost (n=2)	4%
Other comments (n=20), including:	43%
Except for the lawyer, local agencies either didn't have the information I needed or they palmed me off on someone else.	
None of the government agencies would help me.	
They only handed me a list of lawyers who might help me for a fee.	
There are too many conflicting variables (it seems) to get "straight" answers.	
They (and we) were restricted by the mercurial decisions of the State government agency.	
They never showed up.	
They would have better served me and the disability community by going to the Department of Justice.	
Time was of the essence due to a change in my health and mobility; there was no one available to immediately provide relief.	
I had no legal defense for the eviction.	
They said I need to follow through with daughter.	
They were slow to recognize and address the problem.	
I had to go through a hearing to establish I was developmentally disabled—although I had onset at 4 years old and received services from OPWDD since I was a teenager—because there was a claim that there had not been testing and that I couldn't prove I was, for instance, on the autistic spectrum before I was 18. I am now almost 35.	
There was a lack of funding for the assistance.	
Not enough resources for the agency, or from the agency.	
The local agency that administers Section 8 seemed to not have enough resources available for Section 8 housing in my area (western Suffolk County).	
The help I needed was financially inaccessible.	
The closing costs were a lot higher than the lawyer originally told me.	
They couldn't help with my housing situation.	

Our community (southern tier) has very few suitable housing options for people who can afford rent, but I don't want to spend up to $5K per month for places that are available.	
There are few in-home resources available for an elderly person *with* capacity, which would allow me to stay in my own home.	
There is a conflict in the fire code and the ADA.	

Section VI
Issue Category—Family Matters

Family Matters—type of issue reported:
Of the 123 respondents who reported having serious issues related to Family Matters, 122 described 141 diverse issues, which are sorted into 16 groups in Table 13.

The greatest numbers of issues are related to the respondent's or a family member's health, services, or caregiving needs (53 issues—including 17 for health care, long-term care, and family death; 5 for benefits and services; 12 for caregiving needs or duties; 9 for Alzheimer's Disease and dementia; and 10 for guardianship, trusts, and estate planning), and related to family relationships (32 issues—including 15 for family dynamics; 6 for marriage, separation, and divorce; and 11 for custody, adoption, and support).

Legal Services Initiative
Table 13
Respondent: Type of Issues Reported Related to Family Matters
(n = number of respondents describing the issue)

Health Care, Long-Term Care, and Death: (n=17), including:
Finding accessible healthcare services for myself. Health condition. Cancer. Misdiagnosis of heart disease, ultimately requiring quadruple bypass surgery. My physical health issues were ignored or not believed or followed up on. My wife has health problems that are less serious than mine, but affect her strength and mobility. My condition prevents me from having more children. Seeking health care. Surgeries and health problems due to arthritis. Health issues of my son. Illness and death of father. Loss of parent followed by upset grandchild. Mother died. Parents died and I needed to depend on family for caregiving. Lost my husband to cancer in 2010.

Benefits and Services (n=5), including:
Arranging for my mother to apply for Medicaid in advance of her need for long-term care. Getting assistance with Activities of Daily Living when family/friends are busy--adds to the burden. I need help with virtually everything. My Medicaid HMO has refused over and over and over again to pay for necessary care and prescriptions needed for my multiple, chronic, and very serious health issues---they just want the disabled population dead. Gaps in Medicare.

Caregiving—for Self (n=12), including:
Caregiving. Finding affordable caregiver help. Wife is my lone care provider—no supports available. Getting caregivers to help me live independently at home. My disability creates a greater dependency for me upon my 83-year-old mother and overburdens her. My wife is my caregiver, and she is exhausted because she has been administering IV antibiotics and helping me use a wheelchair following foot surgery. Rely on my family as primary caregivers for my Mitochondrial disease. Trouble finding caregivers. Caregiving while working and child not in school. Coordinating schedules and agreeing on care. I am a caregiver to my sister who is an adult with special needs—on duty 24/7; did not get any help to give me a break, rest, or someone to care for her when I needed to be hospitalized.

Alzheimer's Disease and Other Dementia: (n=9), including:
Alzheimer's Disease. Caregiver for parent with Alzheimer's. Community spouse physically impaired and could not care for dementia patient. Dementia. Dementia compounded with medical needs. My mom has dementia. Mom has Alzheimer's, severe dementia, a broken hip and Stockholm Syndrome—she was institutionalized and acquired bed sores; I took her out to live with me; it was about a year before she/we were able to get help; the entire transition/resolution was profoundly overwhelming.

Guardianship, Trusts, and Estate Planning (n=10), including:
Guardianship. Guardianship because of criminal situation. It was necessary for my mom to get guardianship and be my representative payee. Needed to reapply for Article 17A Guardianship. We established a co-guardianship for my son; it went smoothly, but just took a long time. Had to attain guardianship and alternates for my Mom; had to decide on a home to bring her into; had to get power of attorney. I needed to set up a trust for my daughter. Set up a Special Needs Trust for care—needed a Social Security and Employer Identification Number letter. Estate issues—needed an attorney skilled at this—called legal aid 3.5 years ago, had phone intake and still no call-back or appointment offered even though they said my situation was serious and they'd fit me in quickly.

Family Dynamics (n=15), including:
Coming from a Catholic family, it was difficult to accept the fact that my brother is gay; now that I am older, and wiser I do not see it as a problem. Didn't hear from my Mom. Domestic relationship. Family relationships. Major disagreements with siblings. Got into argument with a parent, resulting in a temporary order of protection. Non-acceptance by siblings. Non-acceptance by parents. Stress from relationship with spouse and trying not to worry the children. Family members don't seem to trust me or believe in my capabilities to perform employment duties or have a say in urgent or family matters. Formerly close, loving, generous family had difficulty accepting my disability and inability to work—has resulted in horrific family strife and loss of family emotional and financial support. Family does not always understand my mental health needs. Elderly parents, thinking they are helping, do things with my personal belongings without my permission; they also put their home in Trust for me without looking into all the options and without including me in the process. A relative has problems with his children.

Marriage, Separation, and Divorce (n=6), including:
If I marry my boyfriend, need to know the effect on my medical coverage, his medical coverage, our finances, etc. Civil union dissolution. Divorce. Went through a divorce--difficult to anticipate whether, in the future, I would need to be on disability because problems were getting worse. Difficult to communicate in mediated divorce.

Custody, Adoption, and Support (n=11), including:
Adoption. Child custody. Child support. Custody following divorce and remarriage. Separation from spouse and loss of child custody. Relinquished custody of children. My daughter needed to be adopted, but I wanted to be in her life. We have had a foster child living with us for three years; the parent's rights were terminated and Child Protective Services tried to work with us, but the whole process was very confusing and we did not have legal representation.

Abuse and Neglect (n=15), including:
Abusive. Assault and threatened by stepfather and had to move out of home. Domestic abuse. Childhood abuse and neglect. Order of Protection through Family Court. Did not grow up in a safe environment. My spouse was being verbally abusive. My Mom is being abused by her grandson. Son terrorized adult daughter even after she moved out. Son/tenant refused to pay rent, left apartment in shambles, threatened me. Told mom and the lawyer that I got molested by father. Trying to get an apartment for my mom who has Alzheimer's and who was emotionally, physically and financially abused by a family member. Fiscal abuse. For financial reasons, had to get housing with a family member who is abusive. My disabled daughter is being financially exploited. One daughter had access to my bank account and was forging checks and not paying bills—let Medicaid, electric, heat, garbage collection, taxes, car insurance lapse.

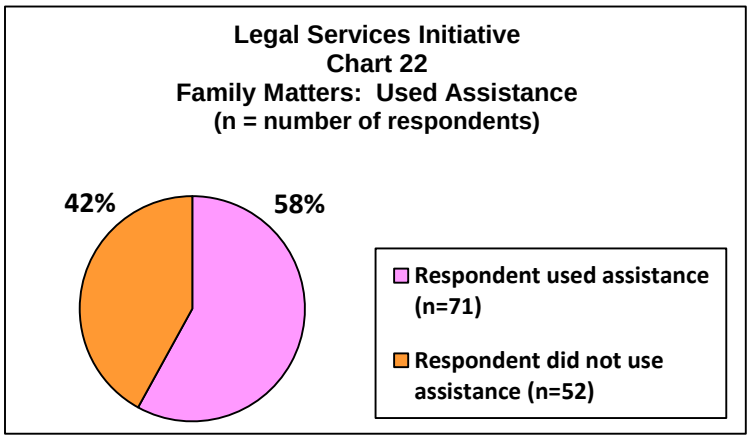
Discrimination and Harassment (n=2), including:
Homophobia due to a lack of proper education about biology has seriously affected my family life, my health, and my ability to feel safe here; I also have difficulty with a community that portrays diversity, yet there is significant evidence of heterosexual privilege in my experiences in work, social gatherings, church, county and local government, and the police department. Segregation in the elementary school setting.

Disability (n=16), including:
Physical disabilities. Mobility impairment after serious surgery—unable to access home. Physical disability—trouble breathing in certain environments or during activity. Became disabled two years ago. Difficulties with socialization, speech, Activities of Daily Living. I applied for and was accepted (just 4 days ago!) for permanent disability. Living with epilepsy is living with uncertainty---one day at a time! Our daughter has severe intellectual

disabilities, as well as physical disabilities--she is non-verbal and non-ambulatory. Severe developmental disabilities. Mental health problems. Difficulty talking about my feelings, so I bottle up my anger and then leave. My mother became depressed from being socially isolated from her peers in her apartment. Trying to work full time with my own health issues while dealing with an adult daughter with severe mental illness and a mother with mental illness.
Housing and Transportation (n=5), including: Housing. Affordable housing. Elevators frequently are out of service in a 14-story building for the disabled and elderly. Inappropriate behavior by my adult children (not power of attorney or health care proxy), which caused the rejection of housing services by a local assisted living facility. I am not happy with my living conditions. Difficulty with transportation needs.
School, Job, and Profession (n=4), including**:** Attending school. Children's school issues. Transferring to a new school. Problems with school district—felt I needed an advocate.
Financial Issues (n=6), including: Not eligible for assistance, but unable to pay for service. Cannot afford durable medical equipment, but make too much to qualify for help. I don't have a job—am 25 and still living with my parents. Not enough resources. Difficulty with disability income. Sole breadwinner—am unable to provide for disabled family members and unable to pay household bills.
Law Enforcement (n=4), including**:** Arrest, incarceration, and probation. Domestic incident involving a stabbing. He did damage to a person and my home. Relative with Autism and mental health issues was arrested.
Regulatory Environment (n=4), including: Child Protective Services wanted to break us up as a family. Lawyers do not provide English As A Second Language interpreters. Mental Hygiene Legal Service assisted on retention hearings. New York law is very different from Florida law—when we moved here, instead of keeping my husband's social security as the community spouse with two minor children, I was expected to pay towards his nursing home care, making life even harder than just the loss of his income, so I got a legal separation.

Family Matters—used assistance:
Respondents were asked if they used the services of a lawyer or other type of assistance provider in order to get help with the most serious issue related to Family Matters.

Chart 22 shows that, among the 123 respondents reporting serious issues related to Family Matters, 58% (or, 71) used assistance to help with the most serious issue, and 42% (or 52) did not use assistance.



Family Matters—why did *not* use legal assistance:
Of the 52 respondents who did not use legal assistance for their most serious Family Matters issue, 48 provided 94 reasons why they did not.

As shown in Table 14, the most prevalent reasons are: the respondent "thought he could handle it himself, or with help from family or friends" (19% of all reasons), the respondent "did not know or think the matter was a legal issue" (17%), and the respondent "did not think he could afford legal help, so did not consider calling anyone" (11%).

Legal Services Initiative
Table 14
Family Matters: 94 Reasons Why Respondents Did Not Use Assistance for Serious Issue
(n = number of respondents reporting the reason)

Reason for Not Using Legal Assistance	Proportion of 94 Total Reported Reasons
Thought you could handle it yourself, or with help from family or friends (n=18)	19%
Did not know or think the matter was a legal issue (n=16)	17%
Did not think you could afford legal help, so did not consider calling anyone (n=10)	11%
Could not afford the cost the legal provider said they would charge (n=8)	9%
Did not know where or how to find legal help (n=7)	7%
Called someone, but they never called you back (n=7)	7%
They refused to take your case (n=5)	5%
Spoke to someone, but they said you did not have a case (n=4)	4%
They said they did not handle your type of problem (n=2)	2%
Waiting list for getting legal help was too long (n=2)	2%
Had no way to get to the lawyer's or agency's office (n=2)	2%
You were concerned that language or communication problems would limit your discussions with the lawyer (n=1)	1%
They would not come to where you lived (n=1)	1%
They wanted to provide help over the telephone, but that would not work well enough for you (n=0)	0%
Other reasons (n=11), including:	12%
Afraid.	
Didn't really have the energy to fight.	
Called adult protective services but they refused.	
Got many conflicting and unclear answers about nursing home without walls possibilities.	
Government agencies do nothing in a timely fashion—I had utility shut-offs; as a disabled senior, they still shut the gas off.	
I called an accessible healthcare program in NYC for a referral to someone in my local area but they did not serve people in my area and, to my surprise, had no information they could provide about local resources; I thought they would have this information because the program is large and seems like it would/could be a good resource for people seeking accessible healthcare.	
I spoke to my therapist.	

It was an issue with the Special Needs Trust—no one seemed to know what to do with it; none of the available pool trusts were explained or offered.	
Legal Services of CNY has refused me any assistance for several years now, in spite of multiple requests for serious denials by my insurance company, including a two-year war to get 7-year-old eye glasses replaced and other health issues affecting my ability to ambulate and be independent, and leaving me in severe pain; my insurance company keeps turning down my provider's prescriptions; I believe my denial of legal services was racial.	
Repair crews come in an untimely manner.	
Seems pretty hopeless as a cause—per Advocates at Independent Living Center.	

Family Matters—type of assistance provider used:
Of the 71 respondents who reported using assistance for their serious issue related to Family Matters, 68 reported the single or multiple types of providers used, for a total of 108 types.

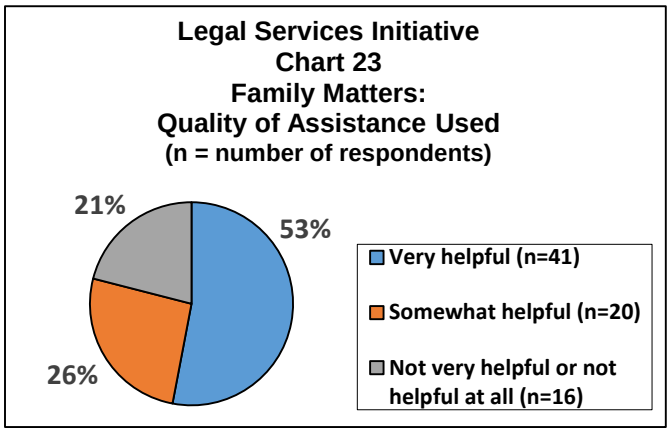
Table 15 shows that a "Lawyer or Law Firm" (31% of all types used), a "Community Agency or Organization" (19%), and a "state or local government agency" (14%) were the types of providers used most often for issues related to Family Matters.

Legal Services Initiative
Table 15
Family Matters—Type of Assistance Provider Used
(n = number of respondents using the provider type)

Type of Assistance	Proportion of 108 Types Used
Lawyer or law firm (n=33)	31%
Community agency or organization (n=20)	19%
State or local government agency (n=15)	14%
Legal Aid Society or other free legal clinic (n=11)	10%
Local Office for the Aging (n=8)	7%
Police (n=8)	7%
Local Independent Living Center or Association for Retarded Citizens (n=3)	3%
Mediation service (n=2)	2%
Ombudsman (n=1)	1
Other type (n=7), including: Contractor. Financial advisor. Family. Realtor and mortgage broker. Internet.	6%

Family Matters—quality of the assistance used, or contacted but not used:
For issues related to Family Matters, 77 respondents rated the providers they used or contacted and tried to use.

Chart 23 shows that 53% (or, 41) of respondents rated the assistance they used for Family Matters as "Very Helpful," and 47% rated the assistance they used or attempted to use as only "Somewhat Helpful," "Not Very Helpful" or "Not Helpful at All."



Family Matters—reasons for dissatisfaction with quality of assistance:
For issues related to Family Matters, 37 respondents reported 68 reasons or comments about why the assistance they received—or attempted unsuccessfully to use—was only "Somewhat Helpful," "Not Very Helpful," or "Not Helpful at All."

Table 16 shows that the most prevalent reasons are: "they were not knowledgeable about my particular problem or matter" (18%), "they did not seem to have my best interests in mind" (18%), and "they did not spend enough time with me" (16%).

Legal Services Initiative
Table 16
Family Matters: Dissatisfaction with Quality of Assistance
(n = number of respondents reporting the reason)

Reason for Dissatisfaction	Proportion of 68 Reasons
They were not knowledgeable about my particular problem or matter (n=12)	18%
They did not seem to have my best interests in mind (n=12)	18%
They did not spend enough time with me (n=11)	16%
They were not competent (n=9)	13%
We did not communicate well—language, speech, hearing, other communication problem (n=7)	10%
They were never available when I needed them (n=4)	6%
The help they provided was not worth the cost (n=3)	4%
Other comments (n=10), including:	15%
Could not get any help from any legal aid resources.	
They didn't explain my options to me so that I could understand.	
Having volunteers review police behavior is unwise, unfair and unethical—I placed myself at further risk by going there.	
I felt like I got the run-around from agencies.	

Nothing could be done.	
The buck was passed—even to this moment I still can't get this issue resolved.	
The paid attorney I finally secured came into the process too late.	
The system could not deal with both the interests of my 12-year-old daughter and my relationship with her due to my disabilities.	
They couldn't find a solution that didn't involve separation.	
We are still in the process of the dissolution.	

Section VII
Issue Category—Money Matters

Money Matters—type of issue:
135 respondents reported 143 serious issues related to Money Matters, which are sorted into 12 groups in Table 17.

The greatest numbers of issues are related to affordability (65 issues—including 43 for the inability to afford daily living and medical expenses; 16 for debt, bankruptcy, and loans; and 6 for bill collectors, billing issues, and credit card problems); and related to health, long-term care, benefits, and services (30 issues—including 24 for benefits and services and 6 for health, long-term care, caregiving, and family death).

Legal Services Initiative
Table 17
Respondent: Type of Issues Reported Related to Money Matters
(n = number of respondents describing the issue)

Type of Issue
Financial—Non-Affordability of Daily Living and Medical Expenses (n=43), including: Bills are overdue and unpaid due to disability, intermittent surgeries, hospitalizations. Cannot afford apartment that would meet my mobility requirements. Cannot afford housing and also meet my other financial needs. Could not pay all bills. Unable to pay utilities—no food and feminine hygiene products. Trouble paying bills. Unable to pay for all medical costs outside of insurance. Can't support disabled family members who are dependent on me. Cannot afford prescriptions. High rent and medical expenses. Hospital bills. Medical bills ($35,000) for hospitalization at time of diagnosis; lost work time, so lost income—difficulty paying bills. Medical bills (many appointments, surgery, etc.). Cannot pay for my medications. Declining financial resources. Didn't know who to turn to. Have problems phone-calling people. Don't qualify for help with in-home care, but don't make enough to hire someone. My part-time jobs are insufficient to afford an attorney or in-home assistance, yet too high to receive assistance since I don't qualify for Medicaid. Forced to move to an apartment—to pay for adult day care for Alzheimer's. High cost of living. Household income decreased. I don't have enough to get by. Just the normal living paycheck to paycheck. Loss of income. Monthly income not enough to cover basic living expenses. No money to pay bills. Not enough income. Not enough money to afford to live alone. Not enough money to live on and pay for non-covered medications or utility bills. The agency cut my weekly money. I don't think my income is at the point where I can collect disability. Lack of cash flow. Living in poverty. Living on low social security benefits; must rely on family members for big expenses. Only receiving social security--am having medication problems—can't work right now. Sometimes my anxiety makes it difficult for me to get to work on time or last through the day, thereby limiting the compensation I can receive since I do not have enough accruals to assist me. Went out on medical leave with greatly reduced income. The round-the-clock care I need to stay in my own home is very expensive and not subsidized in any way—or if it is, no agency was able to help me or

inform me of ways to reduce costs. The penurious Supplemental Security Income monthly check, in total, is a modest rent payment, leaving those already dealing with life-altering disabilities damned to poverty and living in substandard conditions all around. NY State has not increased its share of $87 a month in 30 years, but they have millions to throw at the NY State Fair and sports arenas for Syracuse University.

Financial—Debt, Bankruptcy, and Loans (n=16), including:
Bankruptcy. Chapter 7 bankruptcy. Chapter 13 bankruptcy. Father died, leaving $400,000 in credit card debt and no life insurance. Debt—just recently started working and wanted to work on paying off what I owed. Debts—and, due to illness, extra expenses. Federal student loans. Other student loans. Paying my college loan. In debt from helping to buy car. Serious credit card debt for dental work. SSDI overpayment needed to be paid back.

Financial—Bill Collectors, Billing Issues, and Credit Card Problems (n=6), including:
Bill collectors. Debt collection. Civil judgements. Collections of accounts has been initiated. Creditors are relentless. Utilities still shut me off as a senior and disabled. Billing issues with medical provider. The business sends three different types of statements with little information regarding services. I've struggled with knowing what I owe and don't owe; it shouldn't be this complicated. Billing seems very unfair and highly questionable.

Benefits and Services (n=24), including:
Applying for Social Security Disability benefits. Social Security disability. Social Security. Social Security was discontinued. The Social Security Administration office. Getting survivor SSDI and need to maintain Medicaid. Difficulty being approved for disability and also issues with health insurance. SSDI and public benefits. Couldn't get SSI due to parents' wages even with a Medicaid waiver. Cannot find employment and my Department of Social Services benefits were cut. Lost SSI due to income below living expenses and have an overpayment to re-pay. Understanding and properly following Social Security/Social Security Disability rules while working. When I returned to work, the Social Security Administration did a medical review without notifying me. When her parent died, it restructured her income regarding Social Security Disability—they reduced her amount and took her off the disability insurance, making her get Medicaid and having to re-certify on a consistent basis. Maintaining Medicaid eligibility through the Medicaid Buy-In Program for Working People with Disabilities. SSDI doesn't cover my living costs and health insurance and medication—can't afford a car to get to doctor appointments—injury without a car is very serious; for example, carrying groceries, laundry, etc. Do not know finance amounts concerning care, etc.—difficult to obtain services. Food Stamps very limited. I don't read or write and cannot pay my own bills. I need help from family to get health insurance, social services, etc. I needed to adjust my schedule at work so my income did not exceed Medicaid limits. In order to enter a nursing facility, she had to go on Medicaid. Living off social security benefits when government takes Social Security Part B from my check.

Health Care, Long-Term Care, Caregiving, and Death: (n=6), including:
Family death. Damages and time endured with violations was not compensatory nor pursued sufficiently—cost of corrections were beyond what was being pursued and no consideration for pain and suffering. Mental illness caused overspending. Running out of money for husband's care. Very limited financial resources to pay for assisted living services that accept "private pay" only—very few will accept/transition to Medicaid.

Financial—Taxes and Insurance (n=6), including:
Having taxes drawn on social security. No insurance coverage. Medical insurance. Not receiving what I should from private disability insurance. Taxes.

Financial—Savings, Stocks, and General Financial Issues (n=8), including:
Afraid of outliving savings and leaving spouse destitute. After husband died I had to learn a lot about finances. Needed assistance handling my funds. Needed assistance handling financial matters. Handling my checking account. Managing my bank account. Bank of America requires a $300 minimum balance in my savings account or I'm charged a $5 fee. Banking overdrafts, low on funds, not able to afford to pay for clothing, etc.

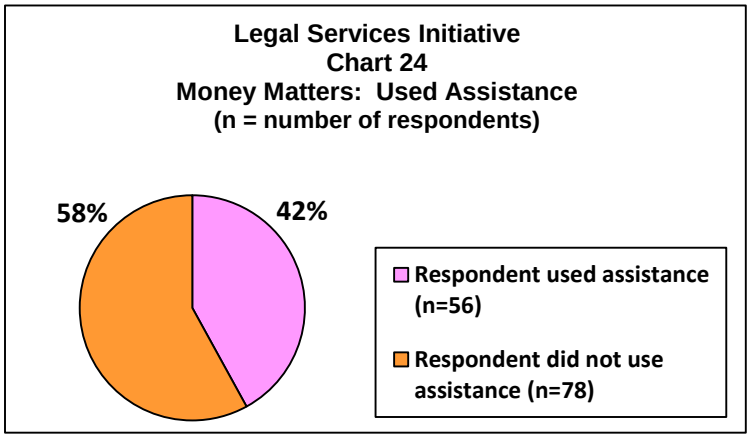
Estate Planning, Trusts, and Guardianship (n=12), including:
Estate planning. Serving as executor for my mother's modest estate. Considered a special needs trust after exacerbation of symptoms and hospitalization. Established a supplemental needs trust for my son. Needed a Medicaid spend-down trust. Trust fund. Trust fund being considered for a Medicaid spend down. Worried about trusts for my son wanted to make sure had proper accounts set up. Special needs trust/will. My trustee and financial planner decided to let go of my lawyer on my trust. Father left a will, and children needed help to protect assets and inheritance and for dividing the inheritance with siblings. Transferring financial responsibility.

Job and Profession (n=12), including**:**
Disabled grandson cannot find employment. Finding a job. Had a hard time finding work. I can't find a job to make money. Looking for more remunerative employment. I became involuntarily unemployed and went on unemployment. Salary. The threat of losing Medicaid benefits—my husband took a job without benefits. Took

medical leaves from full time employment. Unable to work but not accepted for disability. Family's non-acceptance of my qualifications to run the family business.
Abuse, Neglect, Discrimination, and Harassment (n=4), including: Fiscal abuse by family. I was taken advantage of. Parent committed fraud regarding my supplemental needs trust when I was a teenager; refused to sign authorization to correct the trust documentation. Identity theft.
Family Dynamics (n=3), including: Daughter who lives with me is stealing my Social Security and not paying bills. Divorce. Child support was reduced.
Housing and Transportation (n=3), including: Clean out and sale of home, handling bills. Got evicted and was homeless. Unable to pay mortgage and basic bills—foreclosure and now behind in rent.

Money Matters—used assistance:
Among the 135 respondents reporting a serious issue related to Money Matters, 134 reported whether they used the services of a lawyer or other type of assistance provider in order to get help with the most serious issue related to Money Matters.

Chart 24 shows that 42% used assistance for their serious issue related to Money Matters, and 58% did not use assistance.



Money Matters—why did *not* use legal assistance:
Of the 78 respondents who did *not* use legal assistance for their most serious Money Matters issue, 72 provided 114 reasons why they did not.

Table 18 shows that the most prevalent reasons are: the respondent "thought he could handle it himself, or with help from family or friends" (24% of all reasons) and the respondent "did not know or think the matter was a legal issue" (22%).

Legal Services Initiative
Table 18
Money Matters: 114 Reasons Why Respondents Did Not Use Assistance for Serious Issue
(n = number of respondents reporting the reason)

Reason for Not Using Assistance	Proportion of 114 Total Reported Reasons
Thought you could handle it yourself, or with help from family or friends (n=27)	24%
Did not know or think the matter was a legal issue (n=25)	22%
Did not think you could afford legal help, so did not consider calling anyone (n=13)	11%

Did not know where or how to find legal help (n=16)	14%
Could not afford the cost the legal provider said they would charge (n=10)	9%
Called someone, but they never called you back (n=4)	4%
They refused to take your case (n=4)	4%
Spoke to someone, but they said you did not have a case (n=5)	4%
They said they did not handle your type of problem (n=5)	4%
Waiting list for getting legal help was too long (n=1)	1%
Had no way to get to the lawyer's or agency's office (n=1)	1%
They wanted to provide help over the telephone, but that would not work well enough for you (n=1)	1%
You were concerned that language or communication problems would limit your discussions with the lawyer (n=0)	0%
They would not come to where you lived (n=0)	0%
Other reasons (n=2), including: Congress has put limiting constraints on food stamps. I have no clue that I cannot handle my financial responsibilities and no understanding of what my actual responsibilities are.	2%

Money Matters—type of assistance provider used:
Of the 56 respondents who reported using assistance for their serious issue related to Money Matters, 55 reported a total of 86 types of assistance providers.

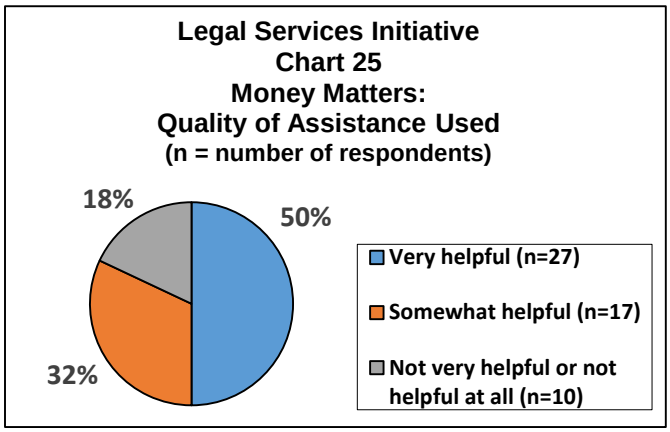
Table 19 shows that a Lawyer or Law Firm (26%) and a Community Agency or Organization (23%) are the types of assistance providers used most often for issues related to Money Matters.

Legal Services Initiative
Table 19
Money Matters—Type of Assistance Provider Used
(n = number of respondents using the provider type)

Type of Assistance	Proportion of 86 Types Used
Lawyer or law firm (n=22)	26%
Community agency or organization (n=20)	23%
State or local government agency (n=13)	15%
Local Independent Living Center or Association for Retarded Citizens (n=9)	10%
Legal Aid Society or other free legal clinic (n=7)	8%
Local Office for the Aging (n=4)	5%
Mediation service (n=2)	2%
Police (n=1)	1%
Ombudsman (n=0)	0%
Other type (n=8), including: Certified financial planner. Financial advisor. Local bank staff. Mormon church. Credit counseling agency. Internet.	9%

Money Matters—quality of the assistance used, or contacted but not used:
54 of the 56 respondents who used assistance for issues related to Money Matters rated those providers.

Chart 25 shows that 50% (or, 27) of respondents found the assistance they used for Money Matters to be "Very Helpful," and 50% found the assistance they used or attempted to use only "Somewhat Helpful," "Not Very Helpful," or "Not Helpful at All."



Money Matters—respondent's reasons for dissatisfaction with quality of assistance:
Of the 27 respondents who rated the assistance they received as less than "Very Helpful," 26 provided 40 reasons why the assistance was only "Somewhat Helpful," "Not Very Helpful," or "Not Helpful at All."

Table 20 shows that the most prevalent reasons given by respondents for dissatisfaction with the assistance received for Money Matters are: the provider "did not spend enough time with me" (23% of reasons) and the provider "was not knowledgeable about my particular problem or matter" (15%). An additional respondent rated the provider as "Very Helpful," but commented that the help provided was not worth the cost.

Legal Services Initiative
Table 20
Money Matters: Reasons for Dissatisfaction with Quality of Assistance
(n = number of respondents reporting the reason)

Reason for Dissatisfaction	Proportion of 40 reasons
They did not spend enough time with me (n=9)	23%
They were not knowledgeable about my particular problem or matter (n=6)	15%
They were not competent (n=4)	10%
We did not communicate well—language, speech, hearing, other communication problem (n=4)	10%
They were never available when I needed them (n=4)	10%
The help they provided was not worth the cost (n=3)	8%
They did not seem to have my best interests in mind (n=2)	5%
Other comments (n=8): They considered it a family matter and would not get involved. If I hadn't done my own research, I would have misunderstood the fiduciary duty of the trustee. The Social Security Administration is hard to deal with for anyone, and we are both trying to solve it together. They could have offered the same help we desperately needed years earlier, sparing us such	20%

despair. He did help, but I needed help from other supports to work with the lawyer and keep him on track. They don't have any connections and give up too easily. Utilities are too powerful over health issues. They wanted to close quickly as they already incurred extensive costs over two years; lawyers settled an award better than HUD is permitted to pursue; the Department of Justice could force greater corrections and higher, more reasonable award; it was not the area of expertise for the mediator.	

Section VIII
Issue Category—Life Planning

Life Planning—type of issue:
Of the 106 respondents who reported having serious issues related to Life Planning, 97 described 103 serious issues, which are sorted into 7 groups in Table 21.

The greatest numbers of Life Matters issues are related to caring for self or others (45 issues—including 14 related to housing, health, long-term care, dementia, and family death, 10 related to caregiving for self or others, and 21 related to guardianship and trusts), and related to future planning and planning documents (25 issues—including 10 for general estate planning and future care of self or child and 15 for planning documents).

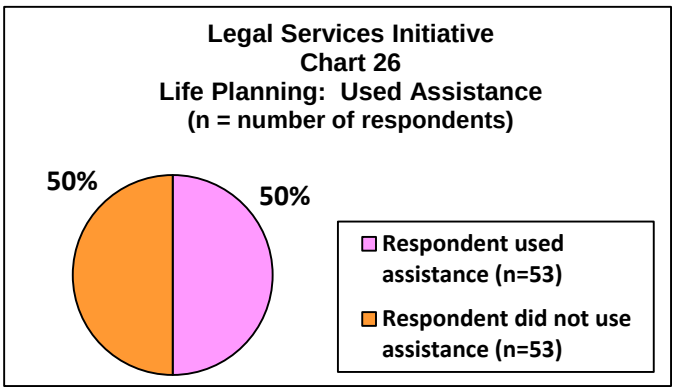
Legal Services Initiative
Table 21
Respondent: Type of Issue Reported Related to Life Planning
(n = number of respondents describing the issue)

Type of Issue
Housing, Health, Long-Term Care, Dementia, and Death (n=14), including: Move to an apartment. Any alternatives to a nursing home when my physical condition deteriorates. I cannot move or relocate until the case is either settled or decided. Dementia care. Dementia care for my mom. My mother had dementia and had to be placed in a nursing home, and she was abused. Nursing home care. Finding a residence that provides 24 hour support. Moving into assisted living. Health problems affecting the rest of my life. Getting out of bed in the morning. Panic. Can't get life insurance for final arrangements. Parent died, which changed her entire way of life and where she lived.
Caregiving (n=10), including: Caregiving issues. Caregiving issues and affordable housing. Caregiving support and resources. Difficulty finding private duty nurses to work in the home and school for our daughter. Finding caregivers. Getting respite care for myself, to give my caregiver some rest. Help at home in the future with assistance. Home care for aging parents. Shortage of Caregivers. Care for family members and elderly parents.
Guardianship, Trusts, and Representative Payee (n=21), including: Guardianship issues. Establishing guardianship. Guardianship and Power of Attorney. I don't know who to name as guardian for my children in case I die in the next 4 years. Mother passed away and sister now pursuing legal guardianship (full). Needed to revise guardianship papers. Personal guardian is not invested. Working on a person to get guardianship and power of attorney to get me into rehab. Having parents who are mid-60's—get things set up for me after they die. Need to file a will and plans for my child in the event of my death—I am a single parent with sole custody. Supplemental Needs Trust. Am in the process of setting up special needs trust with help of lawyer. Setting up a Trust was overwhelming—I had to read a lot about Trusts and went to many estate planning seminars to learn as much as I could. Concern/consideration about setting up a Special Needs Trust. Establish supplemental needs trust, 1st party. Family members set up very inappropriate Special Needs Trust (with bad legal

counsel) that I am not a candidate for, and it will be extremely destructive to all aspects of my life. When should total control be given over? Wanted to have my brother become representative payee for my Social Security income.
General Estate Planning, Future Care of Self, and Future Care of Child (n=10), including: Estate planning. Retirement. Retirement savings. Life expectancy may be shortened—trying best way to plan accordingly (will, life insurance, college savings, etc.). Uncertain of future plans in caring for my disabled child. What will happen to me when Mom is gone? Worry about losing my mom—she is a support. Long Term care planning for self and spouse. **Wills, Power of Attorney, Advance Directive, and Health Care Proxy** (n=15), including: Adding an executor and power-of-attorney. Ascribing power of attorney. Doing advance planning. Will. Living will. Advance directive. Health care proxy. Finding someone to handle affairs after my death. I am unable to draft a will, power of attorney, living will—I applied for, and was accepted (just 4 days ago) for social security disability. Not being able to afford getting a power of attorney as a caregiver of my sister. So far the issue of wills and power of attorney has not risen to the level of needing legal help, but as the disabled person becomes older and more frail, it will. Because I am a same-gender spouse, we had to spend more money than a straight couple would have to in order to do our wills, health care proxy, etc.—we had to have special papers drawn up to avoid any legal challenges to our marriage when traveling out of NYS since our marriage is not recognized in all states; if we had an accident in a state that does not recognize our marriage, the body of the deceased spouse will not be released to the surviving spouse.
Education, Job, and Financial Resources (n=19), including: Education issues. Children's college costs. My college costs. Transferring from 1 college to another. Future plans or care or education for disabled child. Family would not support or approve of any of my career planning. Finding a job that she can handle. Finding employment and money for rent. Finding housing and a job—getting back to normal. Finding work, so I can live by myself instead of with family. My career ended due to illness. Went out on medical leave, then retired. Not finding work, so that I can, with SSA, calculate my SSAR and find a Roth IRA Plan. Declining financial resources. Don't qualify for in-home care providers and can't afford to pay. Don't know how I am able to live on the resources I have in the years to come. I want to move out and live independently, but I can't afford to. I'd like to attend graduate school, but I'm having difficulty locating funding. Need the service, but can't pay for it. No finances for funeral expenses or to continue my education.
Managing Daily Life, Finding Resources, and Understanding Rights (n=14), including: He wants to move closer to his family. How to manage money and be successful. I am 38 and I am working labor jobs because I didn't know how to get help until now; my aunt is helping me—I am also from another country, so that makes it harder with cultural challenges. I need help with paperwork for reimbursable funds (i.e., medical expenses, mileage, and service dog). Inability, due to disability, to plan my affairs and meet responsibilities. Lack of services for care. Managing student loan process. My current girlfriend is pregnant, and I have no understanding of my financial responsibility. Need a handicap parking tag. Organizing and maintaining personal care services. Understanding my rights. Did not sign up for Medicaid in time. Found it difficult to transition off Medicaid, even though I qualified for comprehensive long-term care insurance. How to qualify for Medicaid for a dementia person.

Life Planning—used assistance:
All 106 respondents who reported a serious issue related to Life Planning also reported whether they used the services of a lawyer or other type of assistance provider in order to get help with the most serious issue related to Life Planning.

Chart 26 shows that half (50%) used assistance for their serious issue related to Life Planning, and 50% did not use assistance.



Life Planning—why did *not* use legal assistance:
Of the 53 respondents who did *not* use legal assistance for their most serious Life Planning issue, 39 provided 82 reasons why they did not.

Table 22 shows that the most prevalent reasons are: the respondent "thought he could handle it himself, or with help from family or friends" (27% of all reasons) and the respondent "did not know or think the matter was a legal issue" (18%).

Legal Services Initiative
Table 22
Life Planning: 82 Reasons Why Respondents Did Not Use Assistance for Serious Issue
(n = number of respondents reporting the reason)

Reason for Not Using Assistance	Proportion of 82 Total Reported Reasons
Thought you could handle it yourself, or with help from family or friends (n=22)	27%
Did not know or think the matter was a legal issue (n=15)	18%
Did not know where or how to find legal help (n=10)	12%
Did not think you could afford legal help, so did not consider calling anyone (n=9)	11%
Could not afford the cost the legal provider said they would charge (n=7)	9%
Called someone, but they never called you back (n=2)	2%
They said they did not handle your type of problem (n=3)	4%
Spoke to someone, but they said you did not have a case (n=2)	2%
They wanted to provide help over the telephone, but that would not work well enough for you (n=2)	2%
Had no way to get to the lawyer's or agency's office (n=1)	1%
They refused to take your case (n=0)	
The waiting list for getting legal help was too long (n=0)	0%
You were concerned that language or communication problems would limit your discussions with the lawyer (n=0)	0%
They would not come to where you lived (n=0)	0%

Other reasons (n=9), including: Hope to talk to a lawyer . . . caregivers disagree. Am just beginning to plan end-of-life issues; the difficulty is that no relative lives anywhere near me, I want to protect my personal property from being taken by DSS; I would appreciate assistance with these matters, but previous denials lead me to expect that I will not get any assistance. I had already entered an agreement with an attorney and the DOJ option was never pursued or proposed, even though DOJ would have served me better. I need a guardian before I need a lawyer to draw up the papers. I will be getting help from an agency in the next few weeks. I will talk to my new service coordinator. Mom is 87 and I'm 61; neither of us have/or can get life insurance for final expenses; also, I'd like help to get a certificate to become a Legal/Medical Transcriber without getting government loans. Not certain who else is funding college costs besides VESID—not interested in taking out loans. There is no assistance in finding Private Duty Nurses.	11%

Life Planning—type of assistance provider used:
49 of the 53 respondents who reported using assistance for their serious issue related to Life Planning reported a total of 77 types of assistance providers.

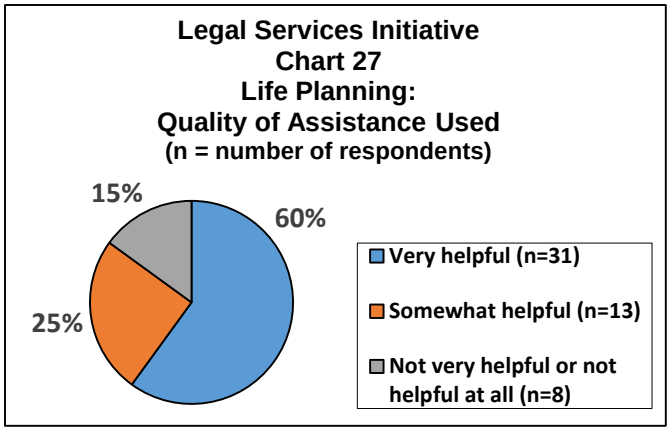
Table 23 shows that a Lawyer or Law Firm (32%) and a Community Agency or Organization (31%) were the types of assistance providers used most often for issues related to Life Planning.

Legal Services Initiative
Table 23
Life Planning—Type of Assistance Provider Used
(n = number of respondents using the provider type)

Type of Assistance	Proportion of 77 Types Used
Lawyer or law firm (n=25)	32%
Community agency or organization (n=24)	31%
State or local government agency (n=9)	12%
Local Office for the Aging (n=7)	9%
Local Independent Living Center or Association for Retarded Citizens (n=6)	8%
Legal Aid Society or other free legal clinic (n=2)	3%
Mediation service (n=0)	0%
Police (n=0)	0%
Ombudsman (n=1)	1%
Other type (n=3), including: A relative who has Social Security Disability. Insurance (SSDI) and someone who helps people get back to work after SSDI. An intern—who did intake incompetently. A therapist.	4%

Life Planning—quality of the assistance used, or contacted but not used:
Of the 53 respondents who used, or attempted to use, assistance for issues related to Life Planning, 52 rated their providers.

Chart 27 shows that 60% of respondents rated their providers as "Very Helpful," and 40% rated the providers as only "Somewhat Helpful," "Not Very Helpful," or "Not Helpful at All."



Life Planning—respondent's reasons for dissatisfaction with quality of assistance:
Of the 21 respondents who rated the quality of assistance as only "Somewhat Helpful," "Not Very Helpful," or "Not Helpful at All," 19 provided 32 reasons why the assistance was less than "Very Helpful."

Table 24 shows that the most prevalent reasons given by respondents for dissatisfaction with the assistance received for Life Planning issues are: the provider "was not knowledgeable about my particular problem or matter" (22% of reasons), and the provider "was not competent" (16%). An additional respondent rated the provider as "Very Helpful," but commented that the help provided was not worth the cost.

Legal Services Initiative
Table 24
Life Planning: Reasons for Dissatisfaction with Quality of Assistance Received
(n = number of respondents reporting the reason)

Reason for Dissatisfaction	Proportion of 32 reasons
They were not knowledgeable about my particular problem or matter (n=7)	22%
They were not competent (n=5)	16%
They did not seem to have my best interests in mind (n=4)	13%
The help they provided was not worth the cost (n=3)	9%
We did not communicate well—language, speech, hearing, other communication problem (n=2)	6%
They were never available when I needed them (n=2)	6%
They did not spend enough time with me (n=2)	6%
Other comments (n=7): Due to family member's age and my illness, not eligible for assistance. It was difficult to access the assistance—extremely time-consuming. Required that I be declared incompetent before appointing the attorney. Shortage of caregiving staff. The problem lies with the local Medicaid office. There are too many "if's" for anyone to give the "right" answer, and as health changes the answers change. They were not able to find an affordable solution to the problem.	22%

Section IX
Issue Category—Dealing with Others

Dealing with Others—type of issue:
91 respondents reported having serious issues related to Dealing with Others (people, organizations, or institutions). 83 of those respondents described 89 serious issues, which are sorted into 7 groups in Table 25

The greatest proportions of issues associated with Dealing with Others are related to various aspects of abuse, neglect, harassment, and discrimination" (22 respondents) and issues connected to law enforcement" (16).

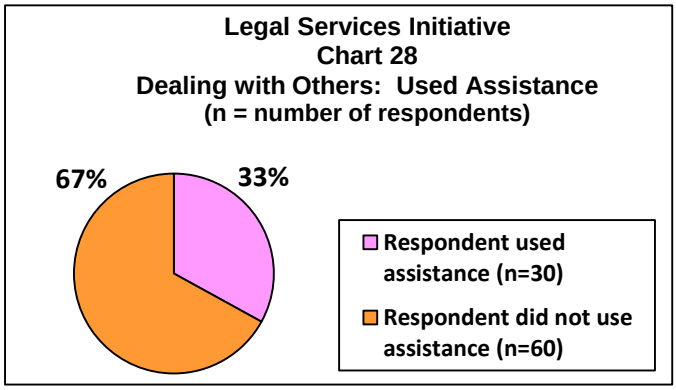
Legal Services Initiative
Table 25
Respondent: Type of Issues Reported Related to Dealing with Others
(n = number of respondents describing the issue)

Type of Issue
Abuse, Neglect, Harassment, and Discrimination (n=22), including: Abusive partner. Bullying. Continued harassment from another tenant in the apartment building. Coworkers lying about me and not following procedure. Dealing with abuse/neglect. Emotional and physical abuse. Drama. Family members not being able to care for me. Harassment. Harassment, stalking, emotional abuse to me and the rest of our family by a sister who has bipolar disorder with features of psychosis and paranoia. I was harassed by the bus driver because I asked for my wheelchair to be secured correctly—it was not and I was "spilled" on a curve. Mental abuse. My girlfriend was bullied by a neighbor who then sent me a nasty letter when I told our Landlord. My trustee and financial manager are making choices for me and are not keeping a lawyer involved with my Special Needs Trust. People take advantage of me. Landlord bullying. People harassing and making false foreclosure claims. As renters, looking for a new home after Hurricane Sandy—prejudice from home owners and realtors. Discrimination by potential landlords due to being disabled and my low Supplemental Security Disability Income. The prejudices of home owners, and the realty agent not wanting to help. As a gay person, there are not enough laws to protect my constitutional rights from hate-filled behaviors by public, police, and lawmakers who hate gays. A false report was filed about me and distributed widely in New York State and with the Federal government.
Law Enforcement (n=16), including: Victim of scam. Credit card fraud. Being charged for several items I did not authorize. Identity theft. Son let his friends scam me and steal money from me—I was alone in the house and was afraid not too give the guy the money. Dealing with theft. Arrested for destroying property. I hurt another person physically—I was arrested and needed legal support. Received ticket for DUI and am working through the legal process with state police and the court. Damages on my property caused by neighbor. People stealing property and the police not doing anything. Landlord taking advantage of disabled Veteran's housing by misappropriating the electricity in their name. Multiple problems with MSC provider, including objective HIPAA violation. Rape. Theft of Supplemental Security Income funds by agency staff member. Left stuck with the payment for the van.
Workplace (n=13), including: Dealing with the County personnel department, where I worked. Get frustrated because employer acts like my condition is fake, denies leave, etc. Getting and keeping a job through VESID. I became unemployed, and I believe it was intentional on the part of my employer because I was trying to form a union at my workplace. I had problems at work with my boss, colleagues, and my clients. Lack of support in making adjustments for my needs in the workplace. Overcoming unconscious bias with County employers. The miscommunications get in the way of my keeping jobs. Work tried to fire me after coming back from being out for mental heath reasons. Workplace issues. Unclear medical leave policy, which is more restrictive at the unit level than at corporate level, and not written down for access. Workplace issues not helpful in having son achieve set goals—repetitive work tasks.

Interpersonal Relations (n=11), including: Constant friction—three handicapped daughters competing for my attention and resources. He does not like the word "no." Major problems with relationship with my sister—caused much stress. Altercation with a neighbor. Difficulty with neighbors when my child is bullied, or when he physically attacks others. Neighbor burns stuff and my house fills up with smoke. Neighbor issues. Neighbor not following the laws in building construction across the street. Insurance company not paying claims to me. Problem with staff and people I live with. Due to my anxiety, sometimes I have a short fuse dealing with people.
Accessibility (n=10), including: Accommodations. Accommodations in the workplace. Voting accommodations. Requesting reasonable accommodations from employer has been a difficult process. Resistance or denial of allowing accessibility modifications. Supervisor didn't understand new needs for reasonable accommodations. ADA and Air Carrier Act violations. Orthodontist office we needed to go to was not wheelchair-accessible. Real estate people are not aware of how to determine accessibility and, therefore, few know the actual amount of available accessible housing.
Social Alienation (n=9), including: Unable to make friends—misinterpretation of others' comments. Disableness—not a contributing member to society. Disability caused struggles for me to deal with others and have a satisfactory outcome from the experience. Fear of any interactions. Fellow house mates made me feel uncomfortable—verbal threats and police called. For the most part, my handicap is hidden and I'm not taken seriously—or when it's understood or noticeable, the perception is that I'm incapable or useless. In high school, people called me "retard." She is taking all my rights away from me and deliberately incites others to take her side, so I live isolated. People do not understand me—keep getting thrown out of gyms. I am a square peg.
Services, Housing, and Transportation (n=8), including: Denial of legal aid. Denial of necessary medical needs. Denial of legal aid. Inadequate and inappropriate health care and support services. Problem with a doctor. Substandard assistance from a licensed home care agency. Living on a bus route. Rejection by an assisted living facility based on the disruptive behavior of offspring that otherwise would have accepted me as a resident.

Dealing with Others—used assistance: 91 respondents reported serious issues related to Dealing with Others, and 90 reported whether they used assistance to resolve their issues.

Chart 28 shows that a third (33%) used assistance for their serious issue related to Dealing with Others, and 67% did not use assistance.



Dealing with Others—why did *not* use assistance:
Of the 60 respondents who did *not* use assistance for their most serious issue related to Dealing with Others, 57 provided 106 reasons why they did not.

Table 26 shows that the most prevalent reasons are: the respondent "thought he could handle it himself, or with help from family or friends" (17% of all reasons), the respondent "did not know or think the matter was a legal issue" (14%), and the respondent "did not know where or how to find legal help" (13%).

Legal Services Initiative
Table 26
Dealing with Others: 106 Reasons Why Respondents Did Not Use Assistance for Serious Issue
(n = number of respondents reporting the reason)

Reason for Not Using Assistance	Proportion of 106 Total Reported Reasons
Thought you could handle it yourself, or with help from family or friends (n=18)	17%
Did not know or think the matter was a legal issue (n=15)	14%
Did not know where or how to find legal help (n=14)	13%
Did not think you could afford legal help, so did not consider calling anyone (n=11)	10%
Could not afford the cost the legal provider said they would charge (n=8)	8%
Called someone, but they never called you back (n=5)	5%
They said they did not handle your type of problem (n=4)	4%
Spoke to someone, but they said you did not have a case (n=7)	7%
They wanted to provide help over the telephone, but that would not work well enough for you (n=1)	1%
Had no way to get to the lawyer's or agency's office (n=1)	1%
They refused to take your case (n=4)	4%
The waiting list for getting legal help was too long (n=3)	3%
You were concerned that language or communication problems would limit your discussions with the lawyer (n=2)	2%
They would not come to where you lived (n=0)	0%
Other reasons (n=13), including: Ashamed and afraid. Did not want to alienate my employer. Fee agencies did nothing—had to hire expensive attorney. Generally, I think the problem is everyone else due to my disability. I haven't decided what to do yet. I got help from my Service Coordinator. I was told not to and was told it was handled, but it isn't. Lack of response by executive director—parent was told if not satisfied son should find another job. One situation resulted in a work-related injury; it's being addressed through workers compensation. Reported fraud to FBI and bank—not yet resolved. Too many other things to address—chose a different orthodontist office instead. Used a psychiatrist. Used mediation help from Nassau/Suffolk Law Services.	12%

Dealing with Others—type of assistance provider used:
The 30 respondents who reported using assistance for their serious issue related to Dealing with Others reported a total of 51 types of assistance providers.

Table 27 shows that a "Community Agency or Organization" (35%), a "State or Local Government Agency" (14%), and the "Police" (14%) were the types of assistance providers used most often for issues related to Dealing with Others.

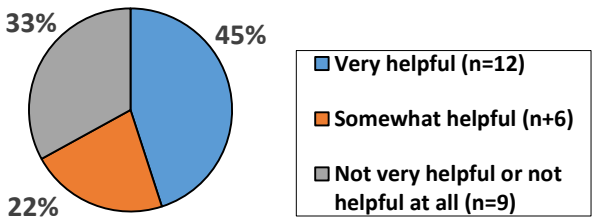
Legal Services Initiative
Table 27
Dealing with Others—Type of Assistance Provider Used
(n = number of respondents using the provider type)

Type of Assistance	Proportion of 51 Types Used
Community agency or organization (n=18)	35%
State or local government agency (n=7)	14%
Police (n=7)	14%
Lawyer or law firm (n=5)	10%
Local Independent Living Center or Association for Retarded Citizens (n=5)	10%
Local Office for the Aging (n=3)	6%
Legal Aid Society or other free legal clinic (n=2)	4%
Mediation service (n=2)	4%
Ombudsman (n=0)	0%
Other type (n=2), including: Housing manager. On line Job Accommodation Network.	4%

Dealing with Others—quality of the assistance used, or contacted but not used:
27 of the 30 respondents who used assistance for issues related to Dealing with Others rated their providers.

Chart 29 shows that 45% of respondents rated their providers as "Very Helpful," and 55% rated their providers as only "Somewhat Helpful," "Not Very Helpful," or "Not Helpful at All."

Legal Services Initiative
Chart 29
Dealing with Others:
Quality of Assistance Used
(n = number of respondents)



Dealing with Others—respondent's reasons for dissatisfaction with quality of assistance: The 15 respondents who rated the quality of assistance as only "Somewhat Helpful," "Not Very Helpful," or "Not Helpful at All" provided 30 reasons why the assistance received was less than "Very Helpful."

Table 28 shows that the most prevalent reasons given by respondents for dissatisfaction with the assistance received for issues related to Dealing with Others are: the provider "did not seem to have my best interests in mind" (20% of all reasons) and the provider "was not knowledgeable about my particular problem or matter" (17%).

Legal Services Initiative
Table 28
Dealing with Others: Reasons for Dissatisfaction with Quality of Assistance
(n = number of respondents reporting the reason)

Reason for Dissatisfaction	Proportion of 30 reasons
They did not seem to have my best interests in mind (n=6)	20%
They were not knowledgeable about my particular problem or matter (n=5)	17%
They did not spend enough time with me (n=4)	13%
We did not communicate well—language, speech, hearing, other communication problem (n=3)	10%
They were not competent (n=2)	7%
They were never available when I needed them (n=2)	7%
The help they provided was not worth the cost (n=0)	0%
Other comments (n=8): Agency replaced money taken and fired the staff member, but staff member was never prosecuted. Due to partial face-blindness, I was unable to describe my attacker to a sketch artist—no arrest made, no charges filed. Conveyed my career goal to the government agency's counselor, who had pre-determined and stated that I had no chance of obtaining my goal even before he ordered a series of physical endurance tests that had nothing to do with my goal/career; I found the tests very demeaning— carrying buckets of water, screwing and unscrewing nuts and bolts in a peg board over my head. I have yet to hear back on the result of my complaint against the Board of Elections. I took the matter into my own hands and notified them as required (serious reportable incident to case manager). Lawyer and Evans Taxpayers Assn only helped—the rest did not help me. Nobody is trained to deal with mitochondrial disease; there are currently no established guidelines or protocols. The County does not recognize its own bias and lack of knowledge of heterosexual privilege and, therefore, cannot consider what gay people are being subjected to; they are not interested in real behavior-based education and the County policy on diversity in the workforce is not even a requirement to read—therefore it cannot be used to address any violations because no one is required to understand the policy as a condition of employment and cannot be held to any punishment as a result of that loophole.	27%

Section X
Respondent—Level of General Concern for 20 Topic Areas

Respondents were asked, "In general, how much concern or worry do you feel about each of the following 20 topics."

Table 29 shows that a greater proportion of respondents rated their level of worry/concern as "A Lot" for 4 topic areas, and a greater proportion of respondents rated their level of worry/concern as "Little or None" for 15 topic areas. Among all 20 topic areas, a range of 20% - 38% of respondents expressed "Some" level of worry/concern.

Legal Services Initiative
Table 29
Resident: General Level of Worry or Concern
(n = number of respondents rating their level of worry or concern)

Topic	Level of Worry or Concern (Proportion of Respondents)		
	A Lot	Some	Little or None
A Lot:			
Your physical or mental health; medications (n=220)	44%	28%	28%
Your income, savings, pension, stock market (n=216)	42%	30%	28%
Long-term care and services for self (n=198)	37%	35%	27%
Government benefits or programs (n=212)	36%	32%	32%
Some:			
Your home, property, or where you live (n=216)	27%	38%	35%
Little or None:			
Police, court system, or law suits (n=208)	9%	20%	71%
Abuse/neglect (physical, mental, emotional, financial (n=210)	12%	20%	68%
Fraud or scams (n=211)	12%	27%	61%
Crimes or safety (n=212)	13%	30%	57%
Neighborhood or community issues (n=217)	13%	31%	56%
Accessibility—buildings, bus, plane, etc. (n=217)	21%	25%	54%
Your job, business, licenses, or business regulations (n=212)	22%	26%	52%
Insurance or taxes (n=211)	25%	24%	52%
School, education, or professional issues (n=207)	25%	23%	52%
Harassment, discrimination, or civil rights (n=214)	21%	29%	50%
Retirement or estate planning (n=211)	28%	27%	45%
Caregiving—for spouse, parent, child, other family member (n=216)	28%	28%	44%
Transportation (n=193)	25%	32%	43%
Debt, bills, or credit cards (n=210)	33%	25%	42%
Family relationships; family matters (215)	25%	34%	41%
Other:			
Climate change; global warming (n=1)		x	
Community recreation opportunities (n=1)			x

Section XI
Respondent—Rating Alternative Resources for Legal Information

Respondents were asked to rate the helpfulness of 10 methods for receiving legal information.

Legal Services Initiative
Table 30
Respondent: Rating Helpfulness of Methods for Receiving Legal Information
(n = number of respondents rating each method)

Method	How Helpful (Proportion of Respondents)		
	Very Helpful	Somewhat Helpful	Not Helpful
Very Helpful:			
A trustworthy referral service that would tell you which lawyer or agency to call to handle your issue, or to tell you which ones serve individuals with limited finances or limited mobility, etc. (n=203).	72%	18%	10%
A telephone hotline where you could call and ask a lawyer questions for free (n=206).	63%	25%	12%
A website that provides legal information (n=201).	60%	19%	21%
A legal guidebook for consumers (n=204)	46%	31%	23%
Community programs on different legal topics (n=197)	41%	41%	18%
Somewhat Helpful:			
Newsletters from attorneys or from agencies on legal matters (n=198)	28%	37%	35%
Not Helpful:			
Radio advertisements (n=201)	6%	27%	67%
TV advertisements (n=202)	6%	26%	67%
Radio or TV programs on legal issues (n=188)	15%	33%	52%
Email notices that regularly send you legal information and resources (n=198)	28%	31%	41%
Other:			
House calls (n=4), including: A person who would make house calls that I could ask. A lawyer that would come to my Special Response Unit to educate me on what services they could help me with. In-house visits by legal advisory teams to explain what help they can provide to persons with disabilities. Visit my program.	x		
Help for or from specific agencies (n=4), including: More help from the Office for the Aging. Non-profit legal services in the area of consumer affairs, government benefits, and financial services.	x		

Trainings for real estate agents and brokers. A dedicated agency for ADA/ACAA compliance and enforcement.			
Internet (n=2), including: A website where you can communicate with lawyers via WebCam or instant message. Interactive webinars.	x		
Personal relationship with attorneys (n=2), including: I have my own lawyer, and I like the firm very much. I know several lawyers.	x		
Pro bono experienced attorneys, as one can readily find in Boston (n=1).	x		
Community outreach in rural areas (n=1).	x		
Support groups; i.e., Veteran friends and community friends (n=1).	x		
Magazine articles; i.e., AARP (n=1).	x		
Materials available in Braille	x		
Teletype and subtitles on all programs	x		

Section XII
Respondent—Optional Comments

Respondents were provided with an opportunity to add optional comments. Table 31 provides the very extensive comments provided by 50 respondents.

Legal Services Initiative **Table 31** **Respondent: Optional Comments** **(n = 50 respondents)**
Employment—training, services, and placement are needed for those who want to work. Housing—rental assistance and greater availability of housing is needed, as well as financial assistance for home ownership without discrimination and racism.
Although I have a license and drive, my car is a 2000 Toyota Camry with 220,000 miles on it. I would use Metrolink, especially in winter, IF the service were available in rural areas. There needs to be more awareness of the Access To Home Program, Able Accounts, and Individual Development Accounts. My family has three lawyers in it and they never heard of many programs that could assist me both now and in the future.
A resource is needed where community and organization leaders can seek volunteer speakers on specific issues.
Affordable legal assistance is long overdue for the disabled and elderly. They are victimized all too often.

Before my daughter was placed, I had many of the problems you described. Since she has been in a good agency, I don't. My main worry is the closing of the workshops . . . where will she go then? WORKSHOPS are my current and main worry.
The impact of disability can be altered by our surroundings—if people are well-supported, they do well and have a good life and are less dependent on the system . . . and the community is enhanced as they take part without fears. If they are denied the same rights and are subjected to a fear of being abused, taken advantage of, or even threatened or killed, or if they are not protected from homophobes and from the police who refuse to treat them equally, people's fears drive their life and that has health-cost consequences . . . the community does not get the benefit of their talents and therefore cannot realize the community's full potential. A rapid re-education is needed, but few would take part unless it is mandated. Homophobia is everyone's problem, but not enough people know that; and if they are aware, they do not act to end it . . . that is why people suffer. Those of you doing this survey—BE someone who changes that today. Use your power to act please.
Don't get rid of 17A Guardianship!!!
Excellent survey. Thank you. This topic is of great import and extremely serious concern. There is essentially no way to get legal advice pro bono or at very low fees in Westchester. Legal Aid is very over-loaded, with absurdly long wait times. I'm still waiting—3.5 years after intake, with assurance that I'd be assigned an attorney asap and two follow-up calls by me, with no response. This is a crisis situation—that legal help is not available for the destitute disabled.
Hold assistance, information, and training at law offices, colleges as adult education classes, or as continuing education classes.
I am the only sibling living in the area where my mother resides. I usually visit between 5-6 times per week (1-2 hours per visit). My stress level is tremendous. I have used the Office for the Aging frequently. I work full time, but there are no support groups in my local vicinity that meet in the evenings.
I am glad you are doing this survey, but please make sure it is published where people/families with all types of developmental disabilities will see the results. The survey is a first step, but really what we need is a more open-ended and descriptive approach first, and then you would probably have designed a different survey format with different questions. I have relied on Nassau Suffolk Law Services because although I have Social Security Disability Insurance and Medicare/Medicaid and have high intelligence, I need assistance from community support workers in many situations, including using legal services. Disability Rights NY, Inc. is failing us. It is letting people and families down when it comes to the problems of dealing with real day-to-day problems—for example, service providers who do not follow the OPWDD guidance document and contract requirements. Then people like me have to turn to local legal assistance, which may not have resources for more than basic mediation. I may need to pursue a formal grievance with Human First (MSC provider agency) and OPWDD all the way to a Medicaid Fair Hearing. I am stuck at this point with worsening medical problems because the Medicaid Service Coordination refuses to deal with health and safety issues that involve local Medicaid Medical Homes and medical providers. DRNY fails us because they do not help with community-based services.
Hope this helps . . . THANK YOU.
I am totally isolated except for home health aides, my daughters, and my 75-year-old brother who drives 50 miles round trip to bring my groceries and supplies and help with occasional home repairs. He is now a co-signer on my checking account and pays all my bills, and he contributes to paying for emergency expenses like taxes and new doors and water heater. He is also almost deaf so is not much help with solving problems. I am very hard of hearing and waiting to see if Medicaid will supply hearing aids. I am on oxygen and unable to get around on my own, but I prefer to stay where I am rather than go to a nursing home. I cannot eat most of the meals-on-wheels that are delivered, so my brother purchases—and my daughter prepares—my preferred foods. My daughter is not always reliable and has acquaintances that are not desirable and one recently injured her.

I answered all the above for my daughter, not ourselves. Our daughter is 33 and was able to get housing and day services; however, these options no longer exist and waiting lists are too long.
I feel that the Veterans Affairs system could be more considerate of their Veterans who lost their lives or have military-service-connected disabilities incurred in service to their county . . . and more considerate of families that have also lost their sons and daughters and who have grouped together and have formed support groups to help each other deal will loss or with their life problems.
I filled this out for my Mom. It is unbelievably hard to navigate the medical/legal world today to just simply live. I have used all the resources I can possibly get my hands on but most of them tell me there are no clear cut answers. Take Medicaid planning for instance—I'm told by a lawyer and a Medicaid employee that I won't know if Mom qualifies until we can make an application . . . that is, until we have bought a house, sold my house, lived together for 2 years and have done the Medicaid spend-down—will I know if we did it right or if I have to sell the house or a car or something to cover some nursing home expenses? Super! I feel so bad for folks who don't have some resources (both family and financial) to get through this maze.
I have a mobility scooter and enjoy using it to travel around Ithaca in the summer, but the sidewalks and crossings are not always easy to negotiate. Since the scooter has no suspension, rough or uneven pavement is a real problem. If the sidewalks were cleared in the winter, I could also use it then, but so far I have not been able to get around in the winter except by car or Gadabout because I cannot count on the sidewalks being cleared. I take medications for asthma, COPD, heart disease, diabetes, thyroid dysfunction, and high blood pressure. My medical copays and expenses last year were over $5,000. I worry at the continuing increase of the cost of health care and prescription drugs, especially the asthma and COPD drugs. I am in the donut hole now and EPIC is helping, thank goodness.
I have answered the questions for my son, except his income.
I have personally been exceptionally fortunate. I recognize that others are not as lucky as I have been. Others need more resources than I have required. Parent support groups have been very useful and supportive.
I provided answers only for my 92½- year-old widowed mother who lives in a nursing facility and gets around in a wheel chair. My brother and I are in our 60's but I did not answer any of these questions from the perspectives of *our* lives.
I realize this survey is concerned with legal assistance, but my main concern is access to services for my young adult son with autism. We can manage the legal system just fine. What we can't find are service providers for social-skills improvement, respite care, community hab, or job opportunities. Additionally, we cannot find enrichment activities within an hour's drive from our home. It is extremely frustrating as time marches on and I watch all of those skills we worked so hard to achieve during his school years slowly fade away.
I started this survey initially on behalf of my daughter, who is disabled. However, I ended up answering questions towards the end as if I was the person completing the survey, sorry. I am disabled as well and the sole caregiver for my daughter who is still living and my daughter who passed away almost 5 years ago due to mitochondrial disease.
I, as her guardian, have filled this out for my sister who is not capable of doing it herself or comprehending it at all. She has the mentality of a small child and is physically incapable of caring for, dressing, cooking, walking alone, or any other "normal" activity herself. There have been problems with the reduction in her social security disability monies and her transportation to and from a Horizon's program she now goes to twice weekly. Originally, they wanted to put her on a county bus, unsupervised with typical citizens and she could never do that with her mentality and seizures; therefore, ARC took her out of that program where she was going 3 times a week in an active program and entered her into this twice-a-week, 1/2 day program where someone from there picks her up, but the pick-up was an argument with the facility before they determined they would continue with transportation—and they actually stated that she wouldn't be able to come at all if we weren't willing to put her on public transportation. I think there needs to be better regulations for those who are physically and mentally handicapped when the family is willing to take care of them at home for as long as they can. The family and the client shouldn't be

punished by reductions in benefits. It is less expensive to keep a member home rather than enrolling them into a group home or nursing home. It saves the State, county and family money and keeps the client's equilibrium more sound when they have already gone through the tragedy of losing, to death, those they trust and love.
If all real estate workers and landlords were aware of how to identify accessible or visitable homes, it would make it easier to identify accessible homes and apartments. Some places could be made accessible with little effort or cost but very few people know how to identify accessibility features. It would be helpful, especially for landlords, if there were commercials that explained the need for accessible housing and the turnover-cost benefits because people who finally find accessible housing rarely leave these settings, as other places that will accommodate their needs are very hard to find. Also, if landlords knew there was such a need, they would more quickly be moved to make revisions to become accessible.
It is way past due that advocates advocate for single child-free adults. There is no "marriage equality" for single child-free adults, who are denied over 1,000 federal benefits given to marrieds. In all but 7 states, single child-free adults are denied any/all welfare benefits based on marital/familial status, which is blatant unlawful discrimination, as well as an incentive to breed hordes of illegitimate children. Singles number 120 million as of the last census; child-free numbers 57 million. Singles well outnumber marrieds and have for years. The 7 states that do give single/child-free some welfare benefits don't amount to a week in a dog kennel. However, we roll out the red carpet for illegal aliens and their endless broods, while we deny decent unemployed American citizens basic survival. Single and child-free in America? You can die in a ditch . . . and no one cares. Need legal aid? If you are white, you won't get any. Given my lengthy, extremely stressful time-consuming experience of trying to get legal aid in CNY, it just ain't there for white folks. This is a game to keep people down, denied 14th amendment rights, and to enrich HMO's that take billions in Medicaid funds and deny necessary medical care. Add to that, denial of necessary legal assistance to fight them just makes people dead, which is what the politicians and others want.
It said something about devices—I wear double hearing aids and can't drive without them.
It was difficult to select the "most important" issue (though I did) because I have the following serious issues: me (Multiple Sclerosis & bipolar disorder); daughter (Cerebral Palsy and bipolar disorder); father deceased; caregiver for mother with Alzheimer's; limited budget (Social Security Disability); harassment and threats from a sister with untreated bipolar disorder (paranoia and delusions); concern that if my daughter leaves to get married, I will have to leave our apartment because it has two bedrooms—if my daughter moves out, there will only be one occupant, so I'll have to find a one-bedroom apartment that takes Section 8 and I'm very concerned that I won't be able to find one. When I looked during 10 months and no landlord would accept Section 8, I was so desperate, I even considered taking a horrible place that smelled like urine (and I keep an immaculate, beautiful, clean-smelling home.) That landlord said yes, but reneged the next day because his partner did not want to take Section 8. I was grateful with that one because it was so horrible, but I could not believe that landlords of such a horrible apartment felt that Section 8 was below them (or was it just that they wanted to cheat the government of taxes and couldn't do that if the actual rent they collect is documented by Section 8.) Thank you for doing this study and for taking the time to read my comments. Would you please send me the results of this study? Can you send it to the email that brought me this survey? Thank you again, and God bless you and your study and everyone participating in this study.
It would be nice to also have this same survey for the caregivers to complete regarding how they feel about these same issues for the disabled individual; i.e., although answering as the disabled individual, there may be little concern for fraud or scam protection, but there may be a high concern from the caregiver of that disabled individual.
Living on Staten Island, I would like to see affordable housing and/or rent controls.
I need a handicapped tag for my spouse's car.
New York Legal Service was a big disappointment when I had to have my guardianship papers changed. The gentleman from that agency sat next to me at the table and never even had the courtesy to introduce himself or tell me what he was doing there! The judge was very smart and pleasant, and the changes were made without complications, thanks to the help of the legal advocate from AHRC who helped me with the wording of the change in the order.

Outreach to provide information is essential, especially for people who are secluded or live alone with physical or mental impairments. Some individuals do not have certain communication outlets, so all of the communication outlets listed in the survey, including radio and television, are essential. Teletype (availability) and subtitles on all programs is important, as well as making braille material for those who are blind. A legal hotline would also be helpful. I don't know if it actually already exists, it may.
Perhaps I was not part of the target audience you really wanted to survey since, although I have disabilities now, I am well taken care of.
Programs and information would only be useful to me if materials were available either electronically or in Braille. Web sites would have to be designed to be accessible with screen readers.
Simpler written and oral interpretation of legalese is crucial. I'm an educated adult, but I can't understand terms used in the law enforcement, legal, and court systems.
Since becoming fully disabled I sought help from EVERY available community and government resource to save my home. I was either referred to agencies that refused or were unable to help, or made to feel my situation was my fault—i.e. "Get a job and things'll get better." I've been looking for a job for over two years. Unconstitutional bias forced me to go on Social Security Disability Insurance and move into senior/disabled housing. I had to depend on friends to get legal help to make a decision on what to do with my home. The ADA was written to help people with disabilities—it hasn't. Why? Because both the corporate and social service communities are close-minded. There are other ways to do things. Am I bitter? Perhaps. Am I angry? Yes. I know I'm not alone in feeling this way. Since moving I've met several individuals in similar situations. I used to wonder why people with disabilities who are intelligent, talented, and caring individuals gave up being productive members of society and chose to live one day at a time on government assistance. After two years of being shunned while giving so much to my community through past employment and volunteering, I now understand. I won't give up without a fight. But the State needs to change things.
Someone to check with the tenants once in a while with mail or their presence. The abuse that goes on inside these apartment buildings is unbelievable. It cannot be done in a group, or people won't respond honestly. If they are met with on a one-to-one basis, they are more likely to fess up to issues. There are children from other tenants calling up neighbors of one lady and telling them off for giving their parent some food and telling them off about parking, calling people stupid retards, calling them F$^Xing stupid.
Thank you.
Thank you. This survey was very comprehensive!
The only reason I have not had legal problems with housing or financial issues is that I live with my parents and they still support me.
The problem I had was finding a lawyer that I could afford and then was accessible. The courthouse was only somewhat accessible—it is an old building and I had difficulty getting through the doors with my wheelchair.
The survey was difficult to answer as a caregiver for my daughter and twins. It was primarily addressed to seniors needing someone to help themselves. Not a temporary 3-months caregiver, I am concerned about a family member of whom she is taking care.
There are not enough legal services for the disabled. The above question (#83) is one of the best questions in the questionnaire since it provides methods that would help the disabled find legal assistance. I hope that some of these methods become implemented or created.
There are too many micro-issues that are adversely affected by the macro-issues of employment, transportation, education, housing, and mobility/independence. We are 25 years and 30 years post ADA and ACA, respectively, and are still overwrought with obstacles that would permit full inclusion.

An ADA/ACAA Compliance & Enforcement Agency must be created and given the duty to ensure that every County, City, Township and incorporated Village, as well as every State has a plan or program in place to ensure equality or will otherwise recommend a workable sustainable plan. Federal law must supersede municipal and State law with respect to full compliance. Penalties must be issued and collected from all public entities including other Federal entities. Private entities must be held to a stricter standard, as the majority of abuses seem to stem from the private sector.
There are way too many agencies being paid that do NOT help anyone. They just pass the buck. We need legal help and financial help. Senior Citizens used to help us, now they don't either. No one has money or advice, and we are being taken advantage of. Utilities lie to us and shut us off; HEAP is not enough, especially during last year's snow storms. Government does not help us, yet they want all our tax dollars and social security. I am a registered voter, involved in my community, a senior and disabled, and the utility companies still shut us off. There is no help for small businesses either. No tax breaks, no utility reductions, no breaks. Time to move. This state is a drain.
For aging adults who have emerging serious health issues, there is a serious need to assist their children with estate planning and especially the difficult issue of convincing a parent to relinquish control of their resources in order to qualify for Medicaid. When my mom finally qualified, it was too late to apply for Medicaid before she passed away. There is a serious need to assist individuals with disabilities in renegotiating their default student loans. The default status compromises their ability to reestablish credit and, in turn, limits their ability for asset accumulation, etc. There is a serious need for oversight of long-term home healthcare agencies—the home health aides are notoriously lazy, lack household management skills (e.g., using a washer and dryer, folding clothes appropriately, ironing clothes, cooking, personal hygiene, etc.). That's not to mention the frequent no-shows, and the theft. There is a serious need for legal assistance in pursuing Medicaid prior approval for durable medical equipment. The hoops Medicaid asks individuals and their doctors to jump through are outrageous and unrealistic. Thanks for your consideration.
There needs to be legislation enacted that doesn't "punish" disabled individuals who have worked all their lives, (contributing to the national economy) but will provide home help once they can no longer work, work only part time, or must work minimally, just to eat and pay rent.
This survey has little or no relevance for my son—he does not need legal help, but does need a group home and transportation.
When I first became disabled, I tried contacting multiple agencies for assistance but continued to come up short. I honestly could not believe how little support there was, starting with the personnel department of Erie County for whom I worked. It just went on from there. When someone is disabled they need assistance more than ever and it is exhausting and frequently a futile use of energy to try to get help from services that are supposed to be helpful. A central service that one can call to be directed to help would be extremely beneficial!
Wish there was some way to find assistance (financial and housework help) so that I could work part-time when I am able to—I have breast surgery coming up and have chronic back pain, which makes it very difficult to work full-time.