

GUARDIANSHIP PROGRAM REPORT 2022





OVERVIEW

One of the primary responsibilities of the Statewide Guardianship Committee is to provide oversight and monitoring of the Corporate Guardianship Program, to ensure program quality and consistent delivery of guardianship services through each Chapter's Guardianship Program. The purpose of this report is to facilitate that work by collecting and sharing information regarding the status of the guardianship program statewide. The narrative and demographic information provided here represents our ongoing effort to collect, evaluate and analyze useful statistics about the people we support. Sources for this report include Guardianship Applications, Serious Incident Reports and Annual Status Reports submitted to the Guardianship Program Staff between January 2022 and December 2022. Additional observations, issues and concerns shared by Chapter Guardianship staff, Committee Chairs and others have helped to inform this report.



DEMOGRAPHIC INFORMATION

Over the past year, The Arc New York Guardianship staff have noted several changes including:

- A 1.97% decrease in the total number of participants in the Corporate Guardianship Program (558 in 2022 to 547 in 2023)

Twenty-eight deaths of individuals supported by the guardianship program are linked to age-related health care needs, and co-existing conditions involving complex, acute, and chronic medical issues including cardiac arrests, sepsis, and COVID-19. Of the twenty-eight deaths, NYSARC served as Primary Guardian for sixteen individuals, Standby guardian for eight people, and Alternate Standby Guardian for four additional people. Of those individuals ten required assistance from The Arc New York Counsel and Guardianship staff with end-of-life 1750-b meetings.

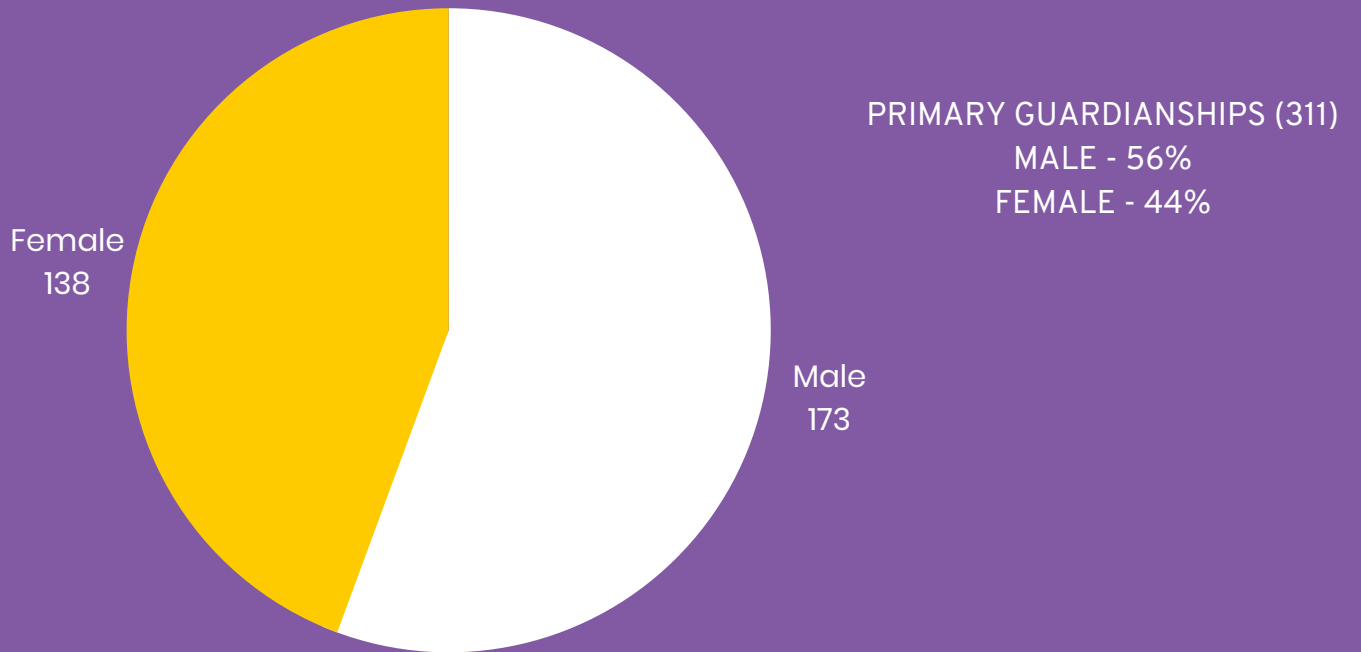
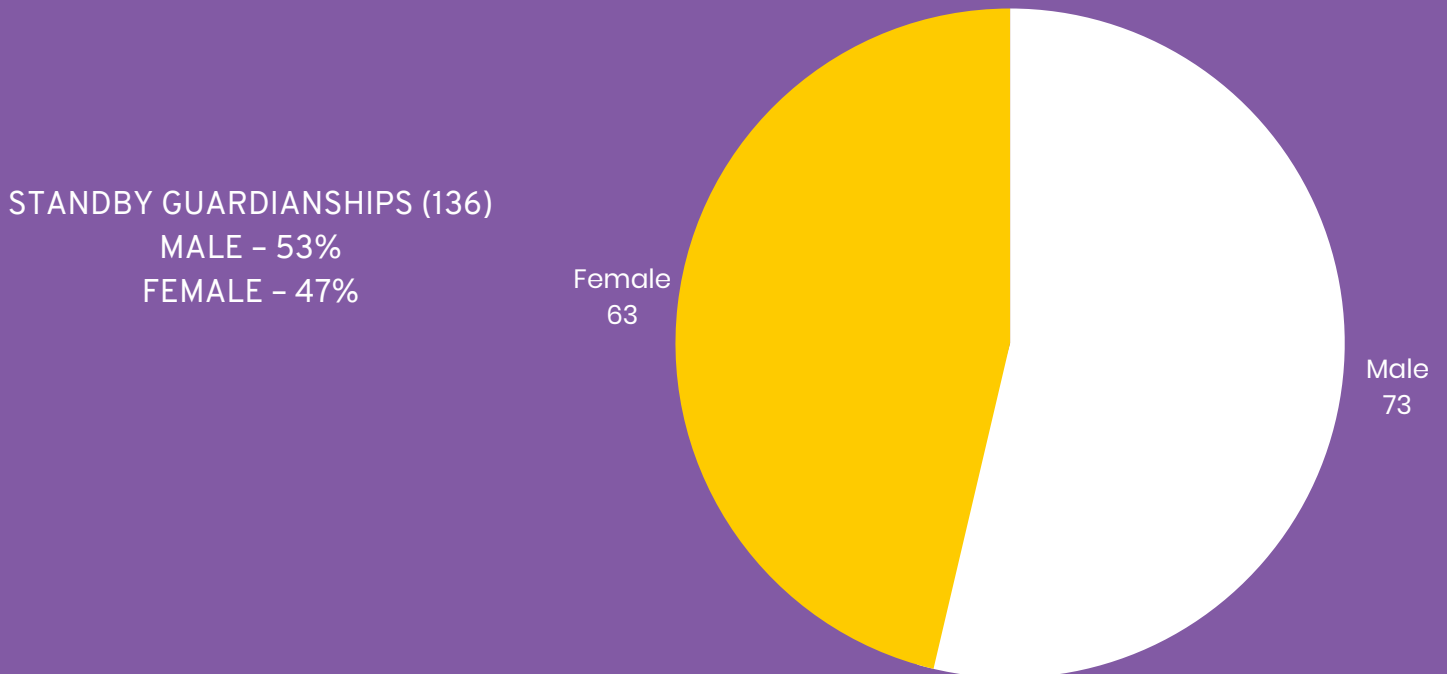
- The Arc New York Guardianship staff have reviewed and processed eighteen new guardianship applications from January–December 2022. The NYSARC State Guardianship Committee approved thirteen applications during this reporting period. Three applications are currently pending additional information from the Chapter before it can be submitted to the State Guardianship Committee for approval.

At the end of 2022, NYSARC was appointed Primary Guardian for 311 individuals, Standby Guardian for 132 and Alternate Standby Guardian for 104 people, for a total of 547 court-appointed guardianships. There are currently 22 applications that have been approved by the State Guardianship Committee, for which we are currently awaiting court approval. This will bring the total number of courts-appointed guardianships to 569.

GENDER CHARTS

As of 1/27/22, NYSARC, Inc. was appointed Primary guardian for 311 people:
138 females and 173 males

The following represents a breakdown of males to females in the Guardianship Program and the ratio is very similar for each Guardianship designation. There are slightly more men than women who participate in the Guardianship Program.

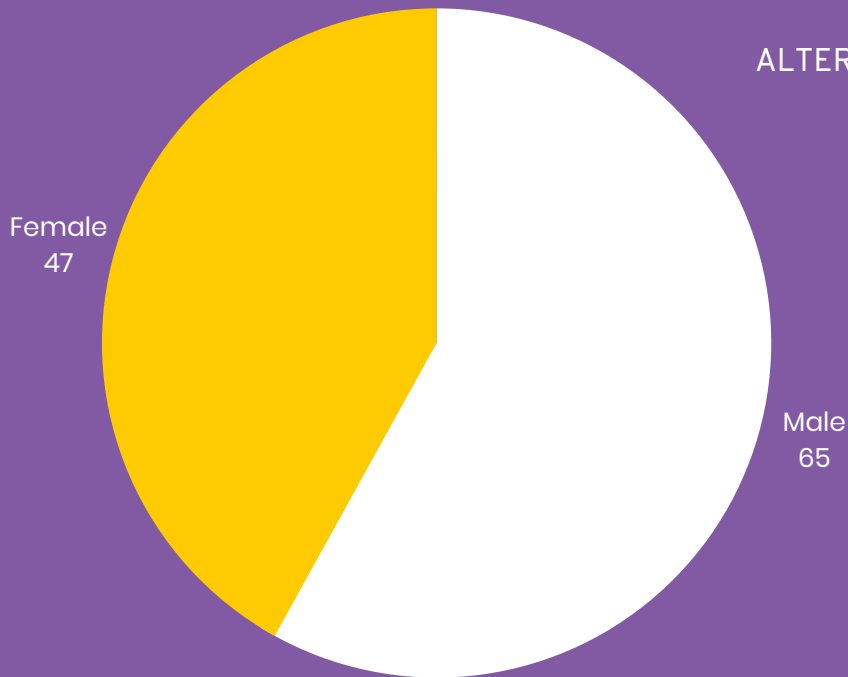


GENDER CHARTS

ALTERNATE STANDBY GUARDIANSHIPS (112)

MALE - 58%

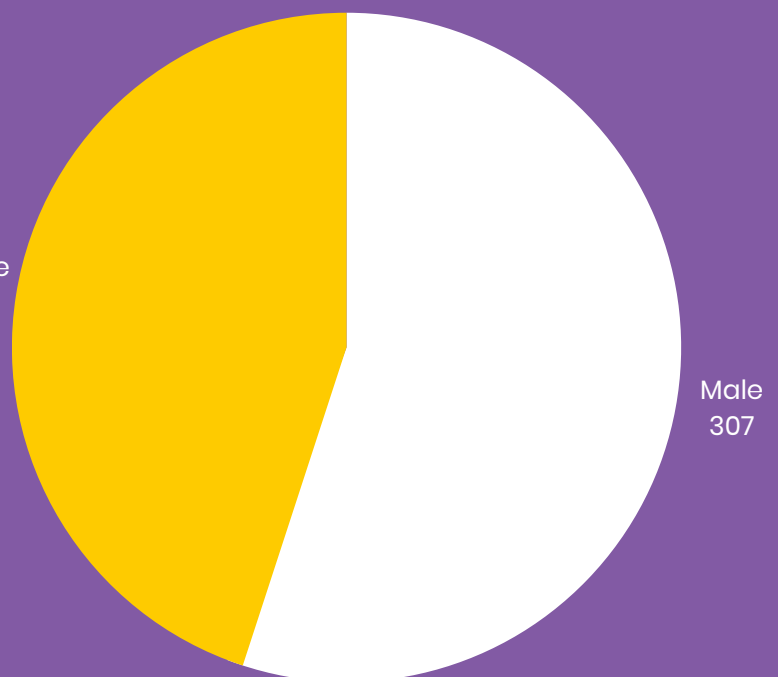
FEMALE - 42%



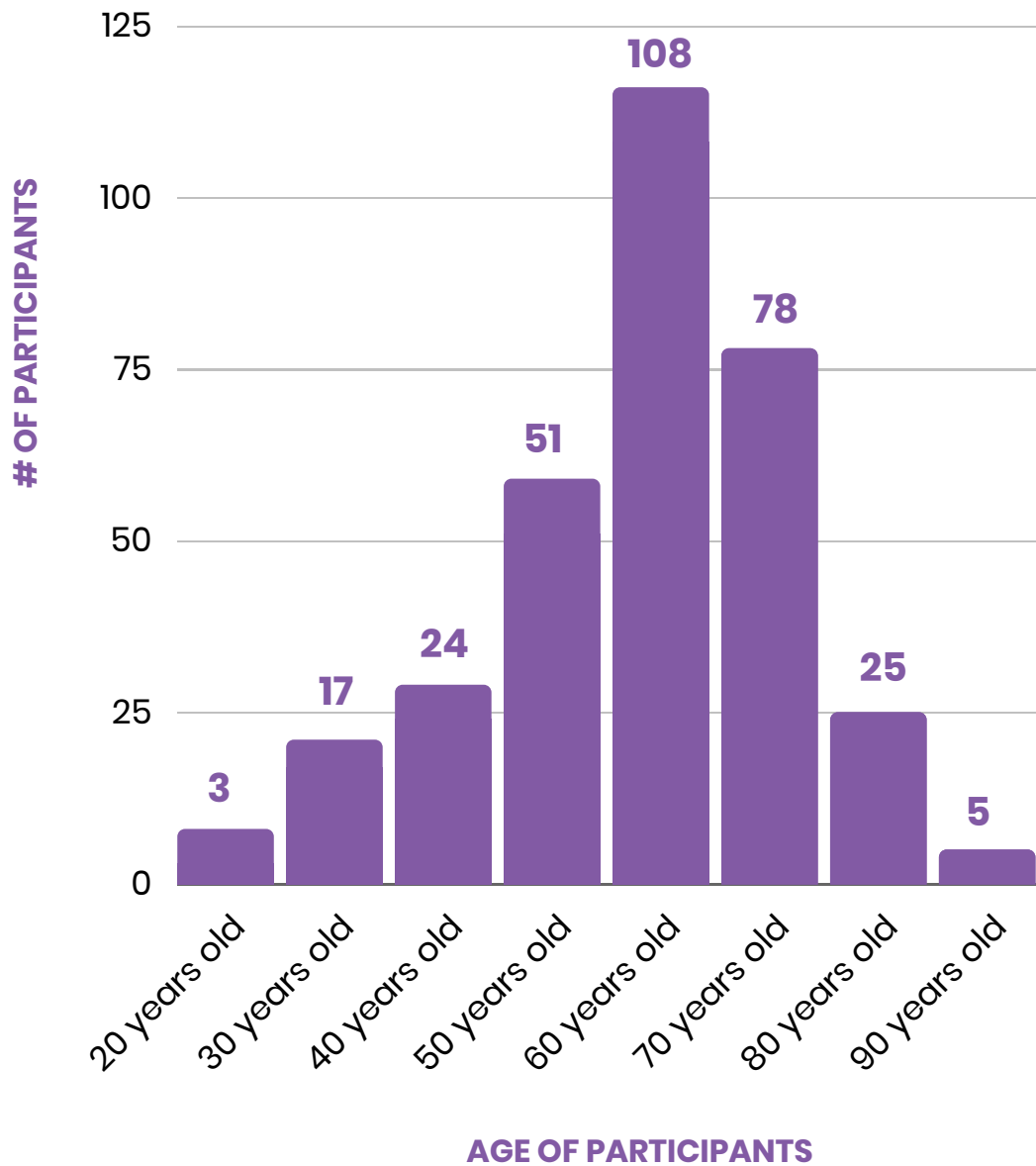
GENDER OF TOTAL GUARDIANSHIPS

Female
251

Male
307



AGE RANGE CHARTS FOR PRIMARY GUARDIANSHIPS

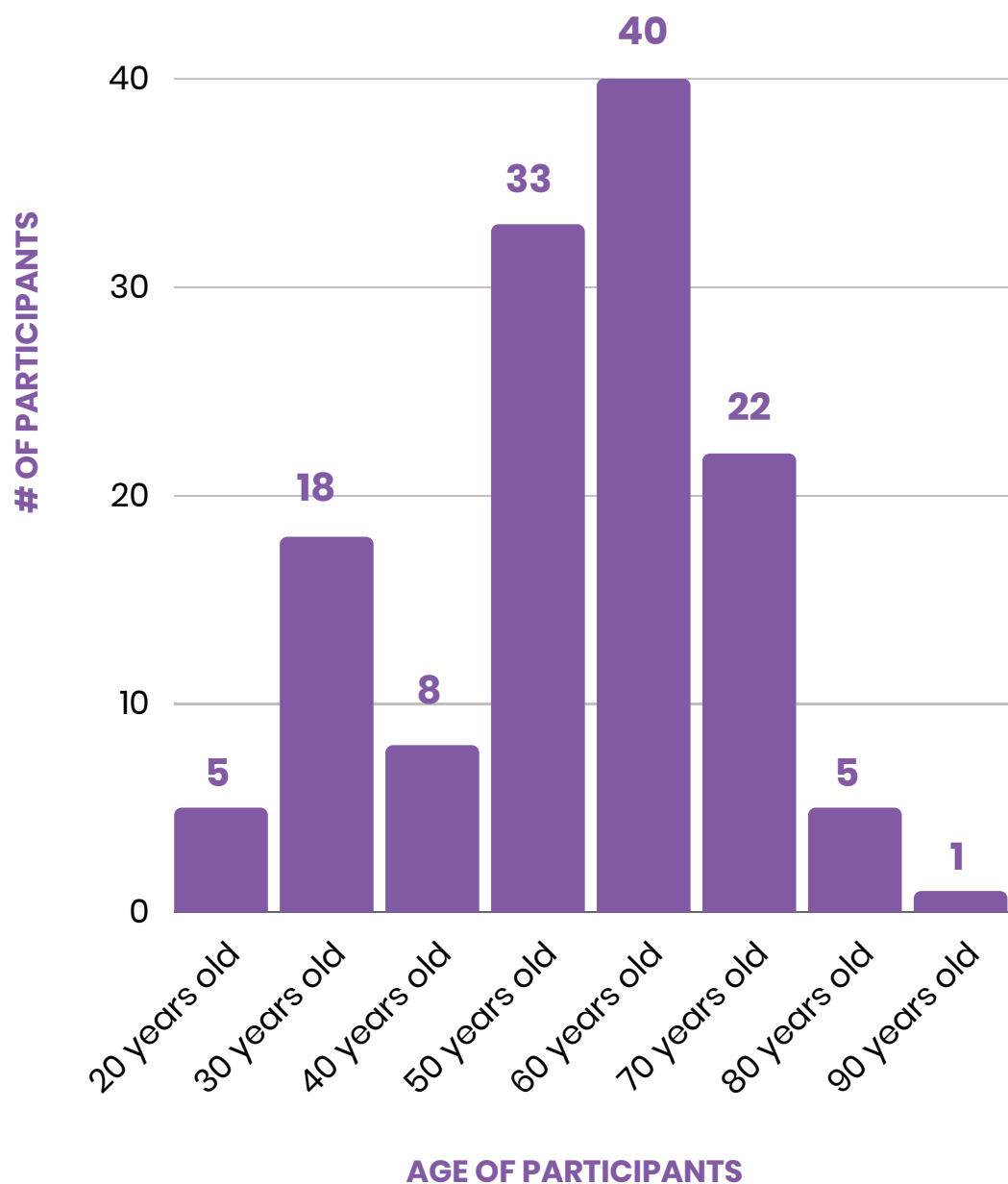


Breakdown of Ages of People Currently being Supported in Guardianship Program:

- 1% is between ages 20-30
- 5% are between ages 30-40
- 16% are between ages 50-60
- 35% of all Primary Participants are between Ages 60-70 – Highest percentage
- 25% are between ages 70-80
- 8% are between ages 80-90
- 1% are between ages 90-100

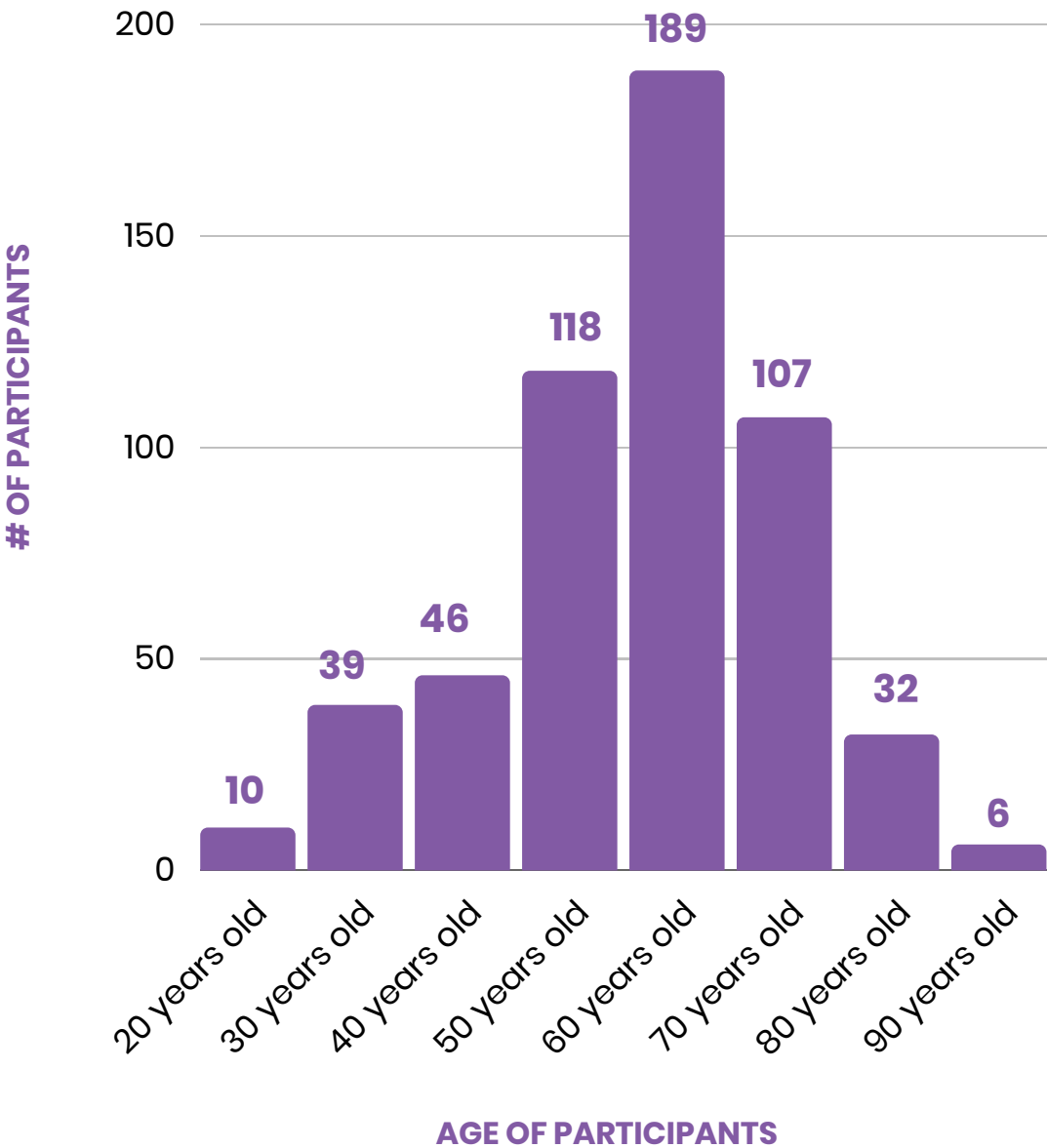
AGE RANGE CHARTS

1/4/23 – Age Range Chart of 132 Standby Guardianship Program Participants



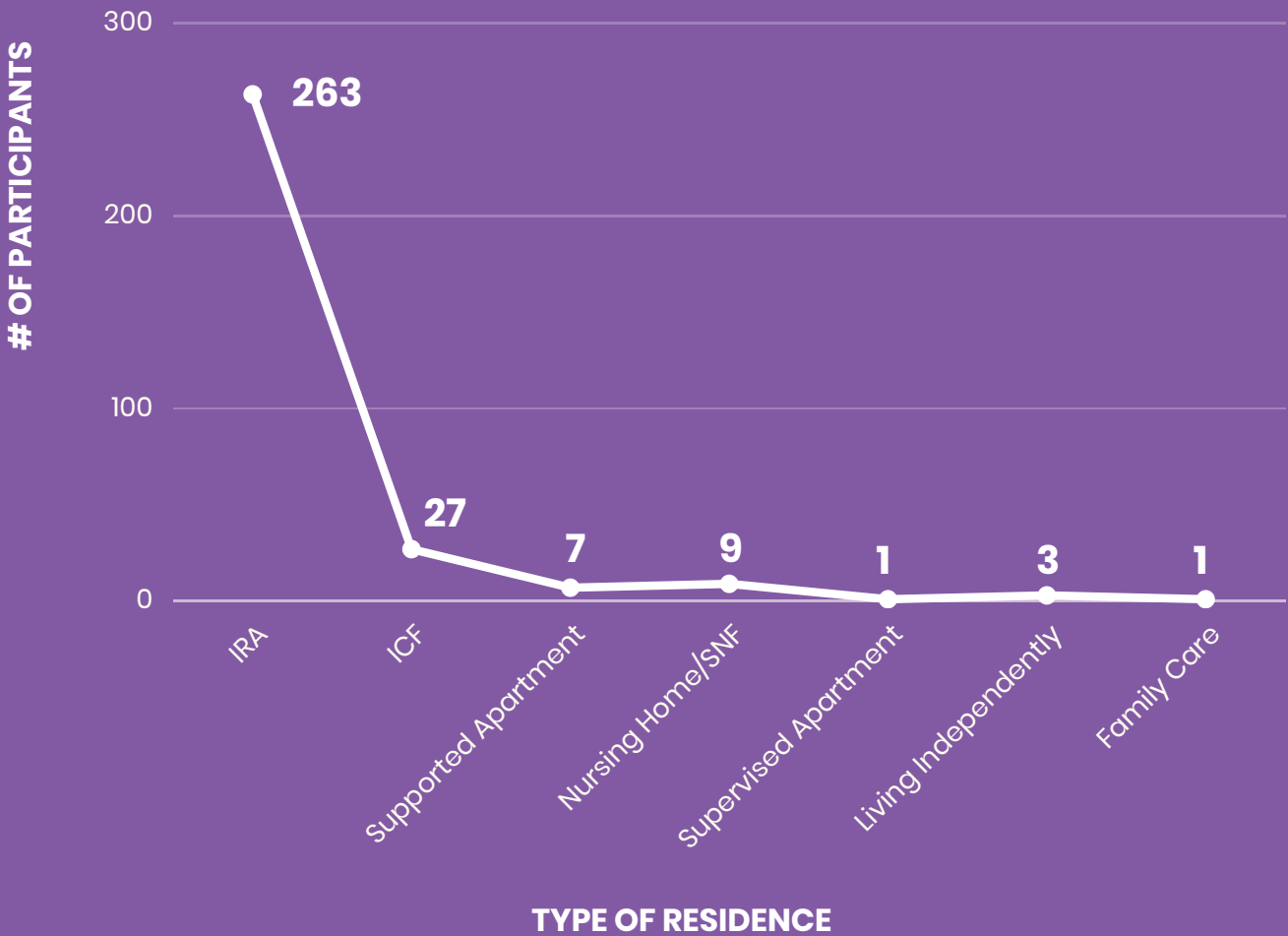
AGE RANGE CHARTS

1/4/23 – Age Range Chart – All 547 Guardianship Program Participants



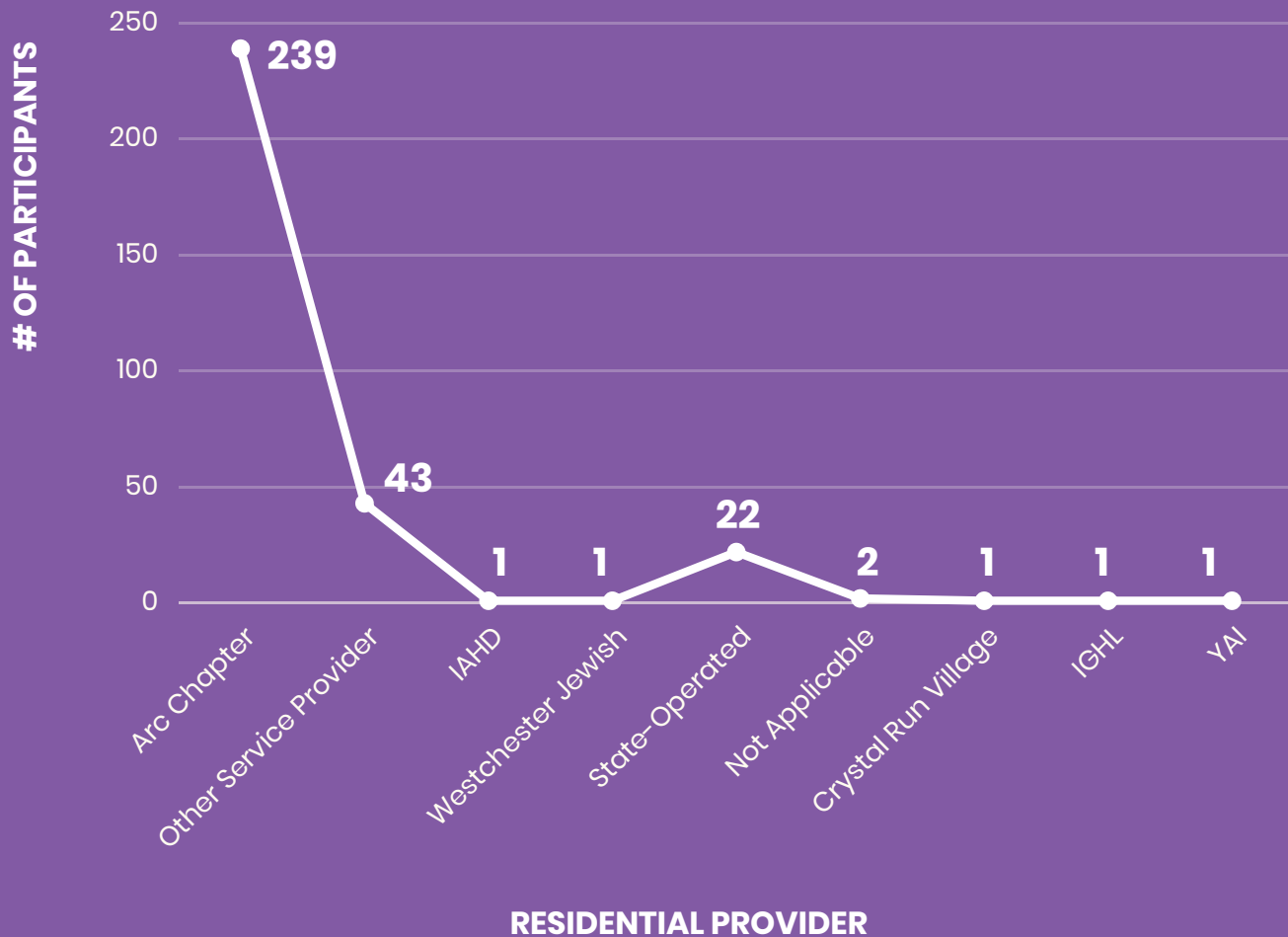
RESIDENTIAL PROGRAM CHARTS

Type of Residential Program for 311 Primary Guardianships



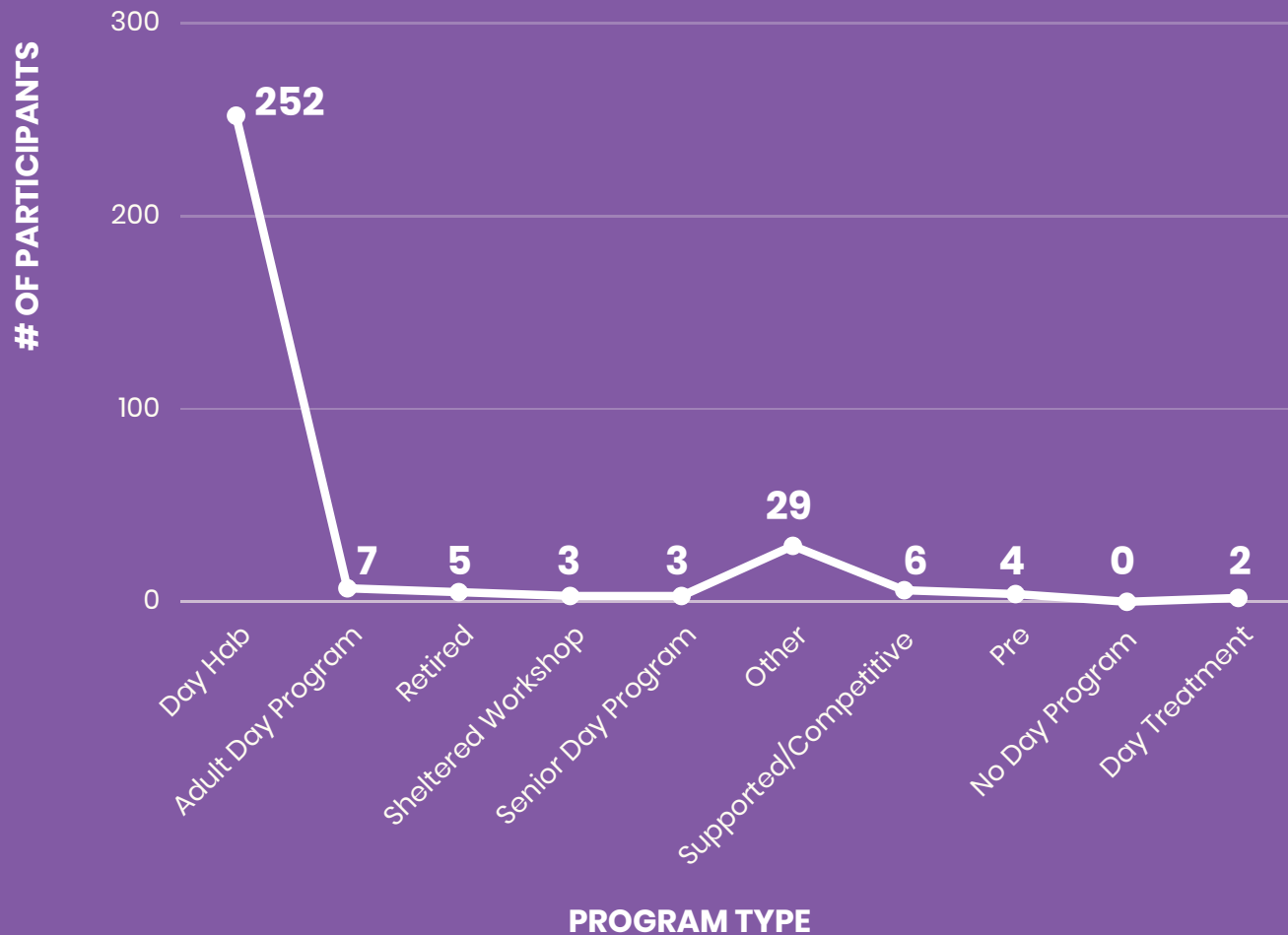
RESIDENTIAL PROGRAM CHARTS

Residential Provider for 311 Primary Guardianships as of 1/4/23



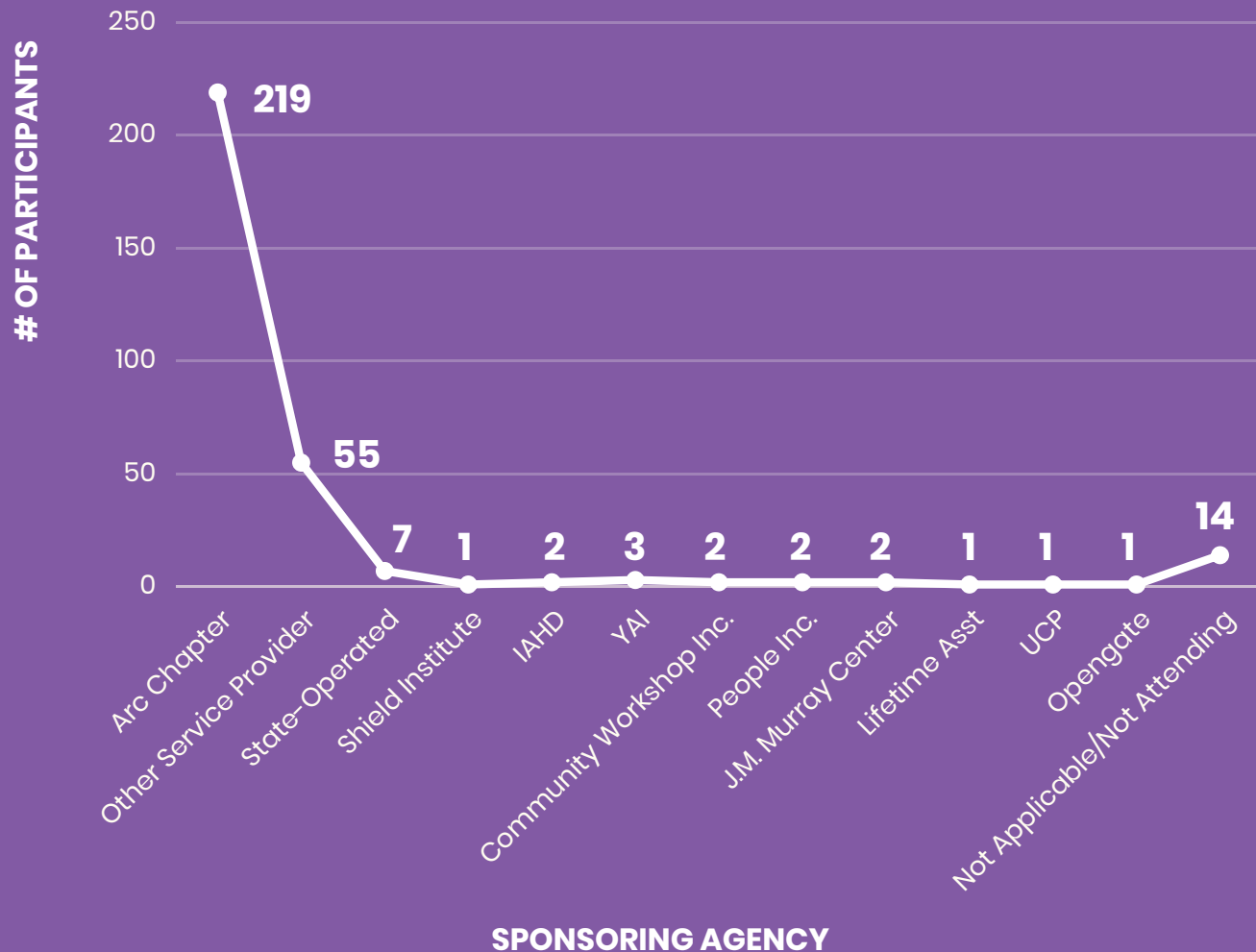
DAY PROGRAM CHARTS

1/4/23 - Type of Day Program - Primary Guardianships



DAY PROGRAM CHARTS

1/4/23 - Day Program Sponsor



To summarize, approximately two-thirds or 216 out of the total of 311 individuals for whom NYSARC is appointed primary guardian are 60 years or older with an average age of 60-70. Out of a total of 132 individuals for whom NYSARC is serving as standby guardian, approximately 72% range in age from 50-70 years old. These numbers increase for the individuals for whom NYSARC has been designated alternate standby guardian, with 80% of 104 people in total with the age range of 50-70 years old. Approximately 72% of the total number of individuals for whom NYSARC is primary, standby or alternate standby range in age from 60-70 years old. Eighty-five percent (85%) of the primary Guardianship participants reside in IRAs, with 76% living in Chapter residences. Out of 311 individuals for whom NYSARC serves as primary guardian, 252 or approximately 81% are attending Chapter Day Hab programs.

Additional Information is provided on the 311 people for whom NYSARC serves as primary guardian:

- 12 individuals have DNR/DNI Orders
- All primary guardianships have a Rep Payee-most are residential providers
- 305 have burial arrangements*
- 93 are the beneficiary of a Trust
- 7 are beneficiaries of a life insurance policies
- 50 have a guardian of their property
- 2 are Willowbrook Class members
- 221 people are on psychotropic medications
- 216 have a behavior management plan
- 4 NYSARC is appointed Article 81 Guardian of the Person (Allegany-Steuben (1) Nassau (1) and New York City (2))

*The Arc New York Guardianship Staff are following up with chapters to address burial arrangements.



THE ARC NEW YORK GUARDIANSHIP PROGRAM OPERATIONS:

As noted in previous reports, The Arc New York guardianship staff support Chapters on an ongoing basis with the administration and operation of The Arc New York Corporate Guardianship Program, including the provision of technical assistance, compliance issues, and education and training opportunities. We continue to see improvement with Chapters' submitting their Annual Status Reports; Guardianship Committee Meeting Minutes; Incident and Event Reports; Program Self-Assessments; Guardianship Financial Reports as well as timely follow up by Guardianship Coordinators in response to Guardianship Program Reviews and other communications with The Arc New York Guardianship staff.

Over the last year, Guardianship staff have provided oversight and monitoring of the Corporate Guardianship Program through a number of activities, including:

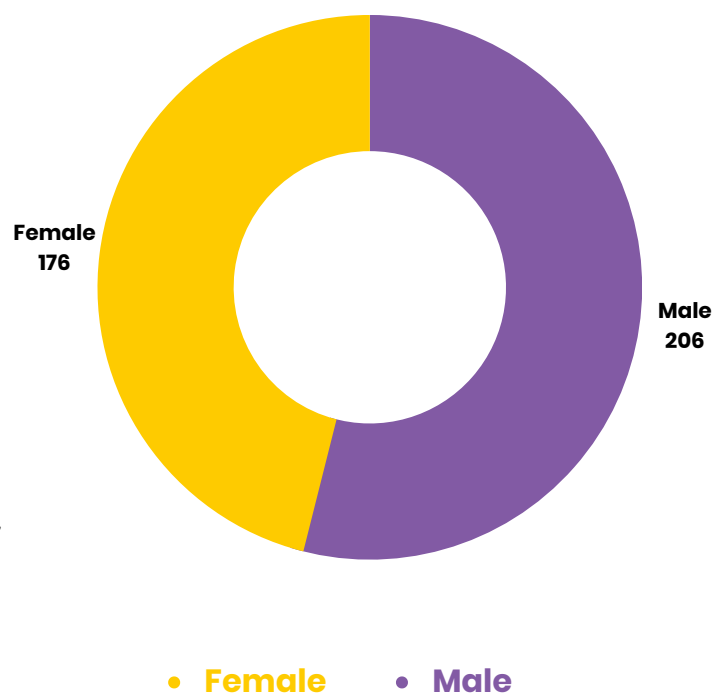
- Examining Annual Status Reports for all program participants
- Reviewing Chapter Guardianship Committee meeting minutes
- Chapter Guardianship Program Self-Assessments
- Reviewing and responding to 382 incident and event reports submitted by Chapter Guardianship staff.

NOTE: This number does not include incident reports that may have been submitted on behalf of individuals whose records were deactivated either due to death or removal from the guardianship succession.

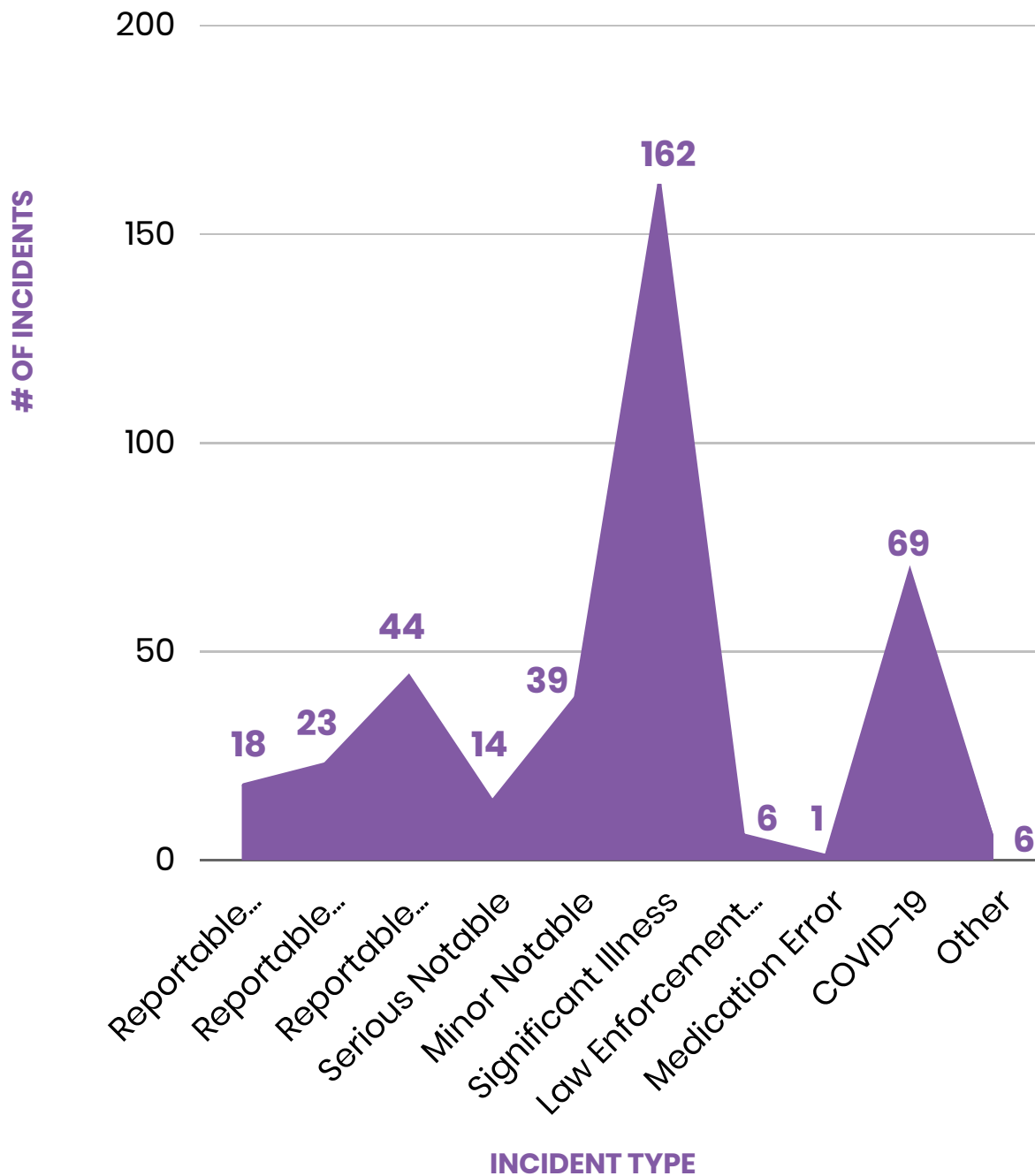
We discovered while preparing this report that once a record is deactivated in our access database, the incidents for those individuals do not appear in the report. We have since worked with our IT department to correct this problem and all future reports will include incident report information for deactivated records as well.

- Chapter Guardianship Program Reviews, which are completed annually and, in many cases, more frequently as needed.

1/4/23 Incidents Sorted by Gender

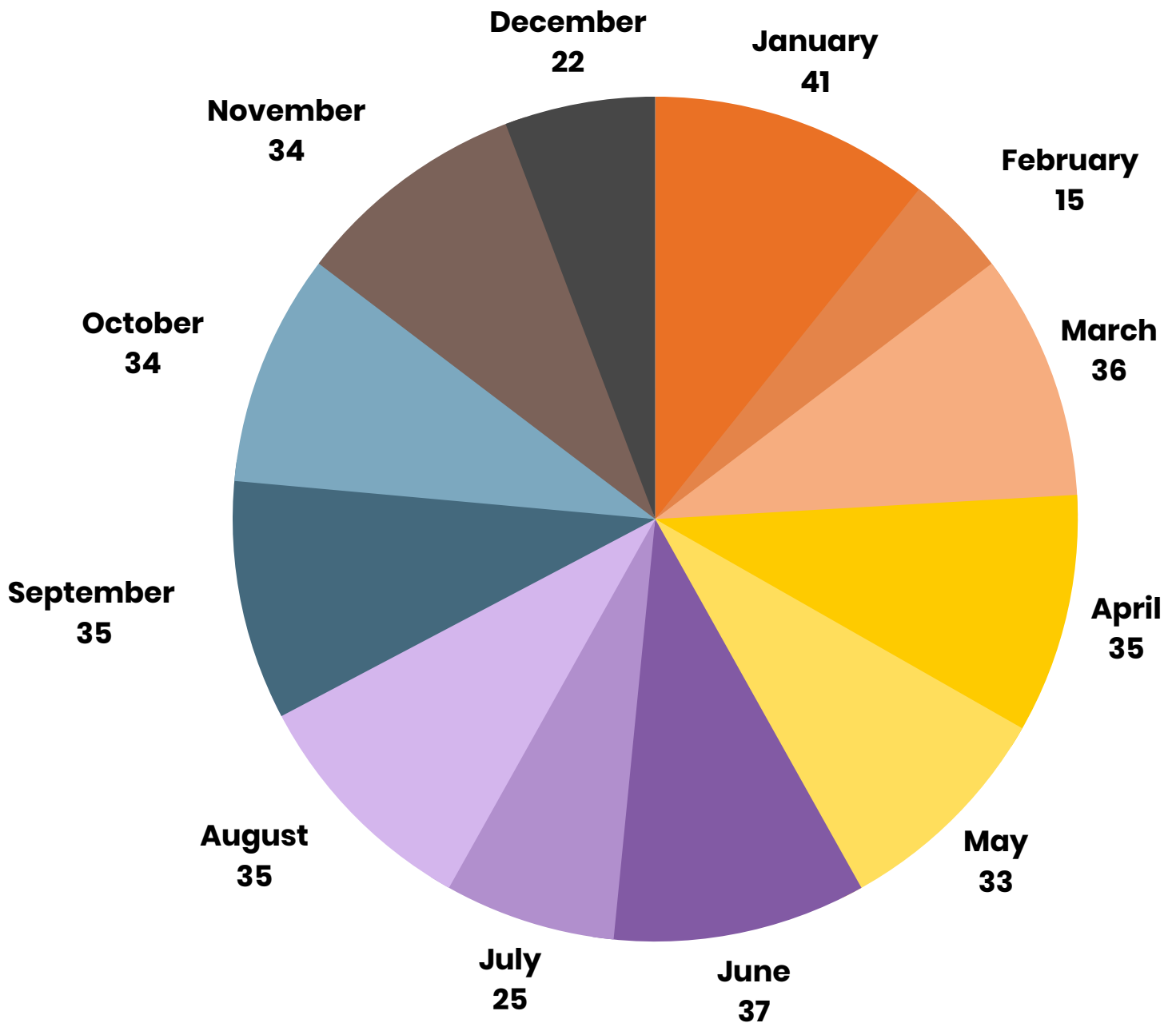


1/4/23 - Incidents by Type



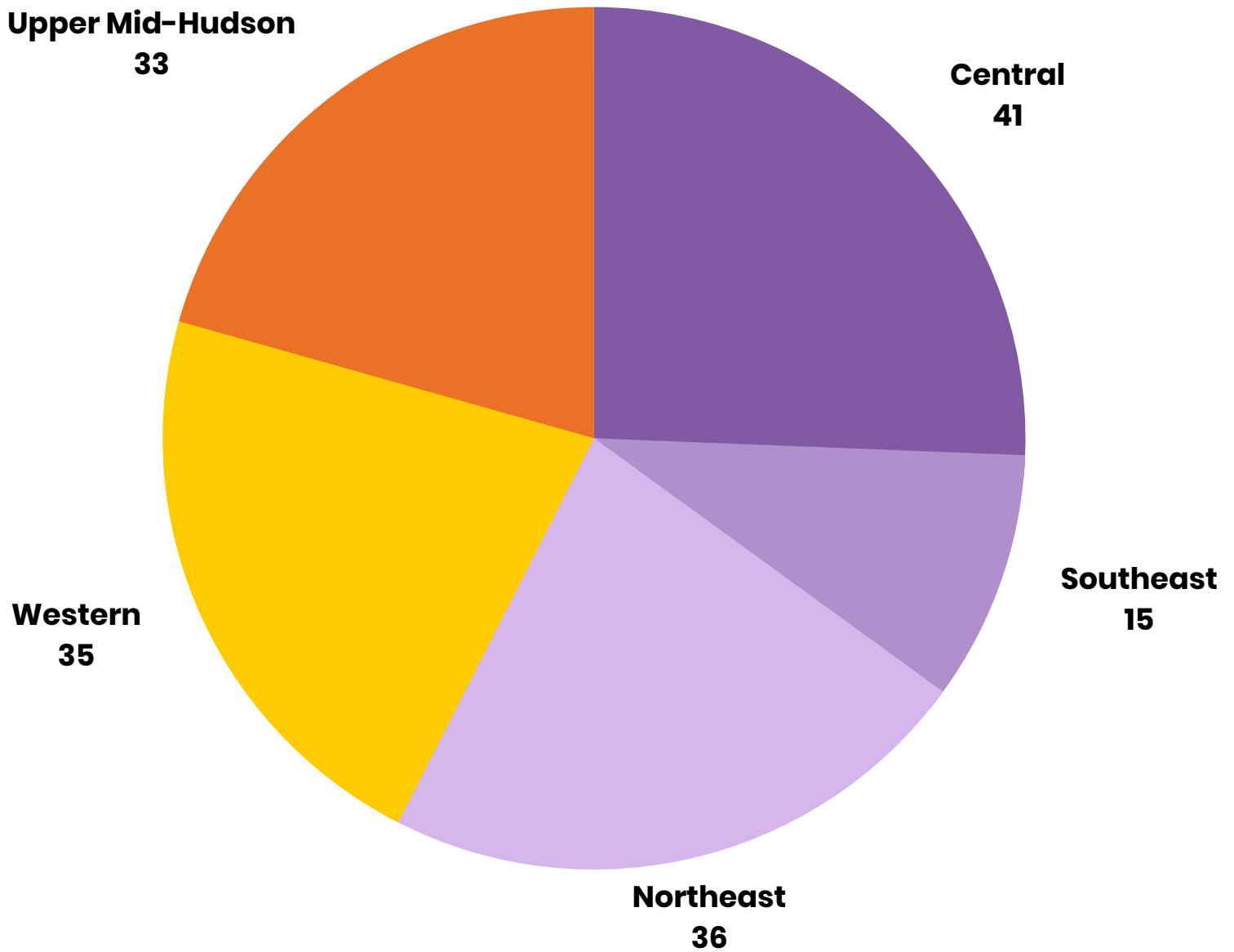
Notable Observation: Most of the serious incident/event reports were as a result of significant illnesses and hospitalizations, including COVID related medical conditions.

1/4/23 – Number of Incidents by Month



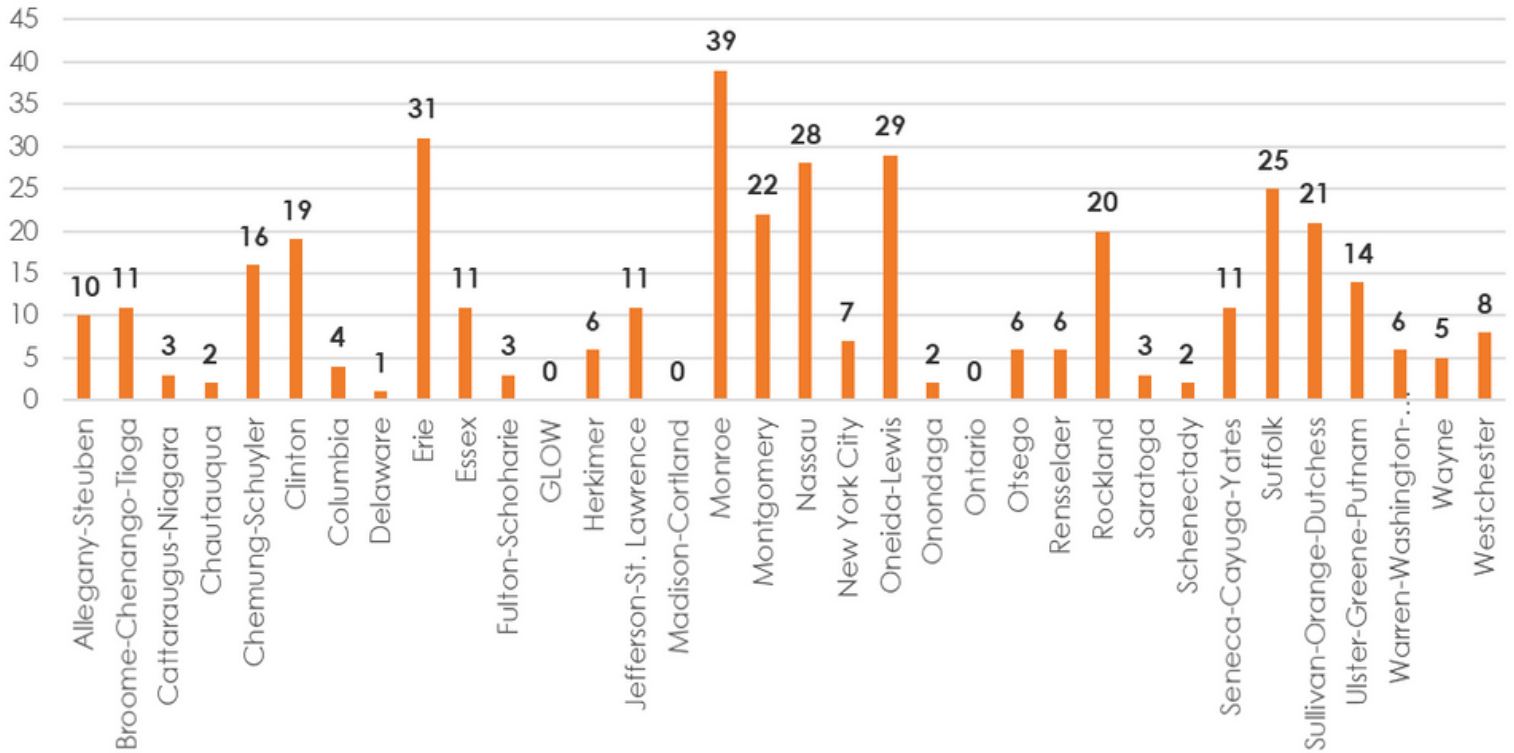
Notable Observation: Most of the serious incident/event reports were as a result of significant illnesses and hospitalizations, including COVID related medical conditions.

1/4/23 Incidents By Region



Notable Observation: Most of the serious incident/event reports were as a result of significant illnesses and hospitalizations, including COVID related medical conditions.

1/4/23 - Number of Incidents by Chapter



1/4/23 - Number of Incidents by Age Group





EDUCATION & TRAINING

Over the past year, the State Guardianship Committee Strategic Planning workgroup on Education and Training in conjunction with The Arc New York Guardianship staff have focused their efforts on ensuring Chapter's Guardianship Committee, leadership and staff receive basic training to support the individuals in their guardianship program. This was partially achieved by developing and/or hosting two webinars. The first webinar was offered by the NYSARC Trust Services and was hosted by the guardianship program. The second webinar was presented on best practices and the relationship between the Chapter Guardianship Coordinator and the Committee chairperson. More than 50 webinar sessions on topics including but not limited to caregiving, end-of-life decisions, dementia, Supported Decision Making and Guardianship have been shared with the Chapters' Guardianship Committees and Chairs. A virtual guardianship symposium and other educational trainings were provided to hundreds of people in the chapters and communities in New York State.

GUARDIANSHIP TRAINING SYMPOSIUM

NYSARC Guardianship staff collaborated with the Training and Education workgroup to develop a statewide guardianship symposium on November 1-3, 2022. The theme for this in-person conference was "Autonomy, Decision-Making Supports, and the Changing World of Guardianship". Although the symposium ultimately transitioned to a virtual event due to continued concerns over the convergence of COVID and the flu, the program was well attended, with full representation from every chapter in attendance. Some of the highlights included the Keynote speaker from Canada who is an internationally renowned motivational speaker on leadership, and there was a session presented by several Surrogate Court Judges who discussed future guardianship reform and proposed changes in court appointment practices.

REGIONAL GUARDIANSHIP SUBCOMMITTEE MEETINGS

Representatives from each Chapter's Guardianship Program are required to actively participate and collaborate in regional guardianship subcommittee meetings at least once a year, in addition to attending the annual NYSARC Guardianship Training Symposium. If the symposium is not held in a given year, then the Chapters' Guardianship Program committee members and/or staff are obligated to have representation at a minimum of two (2) regional meetings.

During the regional meetings, the following topics have been topics of discussion:

- Status of Chapters' Guardianship Programs, including barriers and successes
- Status of guardianship legislative reform efforts and the Supported Decision-Making bill
- Update on The Arc New York Guardianship Strategic Plan and workgroup activities
- NYSARC Trust Remainder fund grant awards and their uses
- NYSARC Training Symposium and webinars
- COVID-19 and its impact on the Chapters Guardianship Program and the people supported
- Best Practices



MEMBERS OF NYSARC STATE GUARDIANSHIP COMMITTEE

Unfortunately, two of our committee members resigned this year, and though they will be greatly missed, we wish them nothing but personal fulfillment and happiness in the next chapter of their lives. The Arc New York Guardianship Staff will pursue potential new members with diverse backgrounds including health and palliative care.

GUARDIANSHIP POLICIES AND PROCEDURES

The Guardianship Strategic Planning Workgroup on Policies and Procedures has successfully reviewed, revised, developed, and distributed all the policies and procedures in the Guardianship manual over the past three years. This initiative was accomplished with additional input from the chapters' Guardianship Programs, the State Guardianship Committee, and final review and approval by The Arc New York's Executive Committee.



FUNDING & SUSTAINABILITY OF CORPORATE & CHAPTERS' GUARDIANSHIP PROGRAMS

A small but intrepid committee of four individuals met on a monthly basis throughout this past year and has drafted a case statement for funding and marketing of the corporate Guardianship Program. Once it has an opportunity to be reviewed and revised by the State Office's Communications Department, the plan is to distribute this marketing tool as a flyer as well as uploading this document electronically and distributing to the chapters and outside potential funders.

NYSARC TRUST REMAINDER FUNDS FOR GUARDIANSHIP PROGRAMS

The Chapters are required to meet a number of requirements throughout the year and The Arc New York Guardianship Staff provide ongoing oversight and guidance to ensure that these are complied with, and appropriate documentation is submitted to the state office. In 2022, the Trustees awarded each Chapter a payment of \$5,000 per Primary guardianship, \$2,500 for each Standby guardianship, and \$1,000 for each Alternate. The NYSARC Trust Management Board has also provided financial support for The Arc New York Guardianship Symposium, which makes it possible for Chapter Guardianship Committee members and staff to attend this mandatory education and training event. The State Office Guardianship Staff and Guardianship Committee are extremely grateful and appreciative of this wonderful and generous support and funding opportunity.





CHAPTER GUARDIANSHIP PROGRAM SELF- ASSESSMENT TOOL

The Chapter Guardianship Programs self-assessment has been completely revised, and divided into two sections, which include a narrative portion and a checklist that addresses basic compliance questions. The intent behind these changes was to design a user-friendly document that could serve as a self-governance tool that enables the Chapters to review and evaluate their program's operations. This assessment tool was completed by all the chapters' Guardianship Committees and staff this past year, and we are pleased to acknowledge the positive feedback submitted by the chapters on the changes that were made to the form.

CHALLENGES, BARRIERS, AND OPPORTUNITIES

As we have done in past reports, we have identified several areas of strength as well as real and potential barriers in providing consistent and quality guardianship services statewide.

- Funding - Although we have received ongoing support and an enormous amount of financial assistance from the NYSARC Trustees in providing guardianship services, these funds may not always be available. Securing dedicated financial streams through blended sources remains a critical area for ensuring the continuity of guardianship services. To assist with this effort and as part of the guardianship program's strategic plan, as mentioned earlier in this report, a workgroup has been developed to assist with determining different ways of securing dedicated funding for the guardianship program.
- Staff Resources - with limited resources, turnover, and so many Chapters not having a backup guardianship coordinator or plan in place, Chapters remain vulnerable. It is our strong opinion that the guardianship coordinator requires at least another staff person who can step into their shoes on a temporary basis when necessary, and have a work plan that offers practical guidance, to ensure a smooth transition of responsibilities. A new Policy and Procedure was adopted this past year that addresses the need for a backup plan and the need for Executive Directors to help ensure the proper staffing and resources are available. This is a topic that needs further discussion with and education for the chapter leadership, so the staff are aware of and understand the purpose and need for this new policy.





CHALLENGES, BARRIERS, AND OPPORTUNITIES

- Consolidation/Unification of Chapters – Chapter unifications can be seen as a challenge/barrier as well as a strength and opportunity to share staff, financial and operational resources. However, there can be disruptions and a learning curve in merging two or more programs together. We have experienced some difficulties in the past couple of years involving a merger of three chapters, and it is suggested that the state office play a more active and consistent role in ensuring a smooth transition and a strong infrastructure is in place to sustain the guardianship Program.
- Consistency – we need to ensure consistency and quality in the delivery of guardianship services by all chapters.
- Older and Aging Program Participants – Our program participants continue to age and require additional support and advocacy to ensure that they are able to age in place with dignity and respect. The Olmstead Act promotes integration of people to live, learn and play in the community if appropriate resources are available
- The Health Care Decisions act (HCDA) – The HCDA often produces additional burdens for the people in our guardianship program, their parents, and families. Though we need checks and balances via MHLS and OPWDD, we also need to develop different requirements to ensure that people with I/DD receive expeditious, compassionate, and appropriate life- sustaining treatment and end-of-life care and support. Additionally, the State office Staff will revise current written instructions and develop clarifying guidance on Article 1750-b end-of-life decision making process.

CHALLENGES, BARRIERS, AND OPPORTUNITIES

- MOLST Checklist – Chapters continue to need support and guidance concerning the completion of the MOLST Checklist form and decisions about the withholding and/or withdrawing of life-sustaining treatment.
- Article 17-a Reform – This represents an ongoing concern. Since there are several proposals being worked on to reform Article 17-A the guardianship staff and committee will need to track the different proposals and prepare a summary of the changes. This past year, we have provided a summary of revisions that have been proposed by the Surrogate's Court Advisory Committee, and, it is important that the Guardianship Program remains current about reform efforts to Article 17-A and Article 81 Guardianship statutes.
- Supported Decision Making – This past August, 2022, the Supported Decision-Making Act was signed into law and the guidelines will be promulgated by August 1, 2023 from OPWDD. We will need to explore all of the implications of providing information, education and training on this model of support as well as how we will integrate it into the chapter's practices on an individual basis.





CHALLENGES, BARRIERS, AND OPPORTUNITIES

- Article 81 Guardianship Appointments – At this time, the guardianship committee has been reviewing requests to serve as Article 81 guardian on a case-by-case basis. We are receiving an increasing number of requests to serve as Article 81 guardian, which has caused ongoing conversations as to whether the mission of the Corporate Guardianship Program should be formally expanded to include Article 81 guardianships. This would be a large shift that would require corporate approval and governance changes at both the Statewide and individual Chapter level. Additionally, consideration must be given to ensure that the State Office and Chapter guardianship programs have appropriate training, infrastructure and resources to meet the additional legal requirements that come with Article 81 guardianships.
- Appropriate residential placement and other Supports for people with co-existing, complex medical and behavioral conditions and needs. This is a major area of significant concern for the Guardianship Program, and the staff plan to meet with professionals and experts at the State Agencies on Aging, Long-Term Care, and Nursing Home advocacy organizations for future collaborative, educational and resource purposes.

CONCLUSION

This report represents a summary of several activities accomplished as well as currently being addressed by the Guardianship Program volunteer committee members and staff. This report is also intended to identify the supports, services and oversight duties provided by The Arc New York State Guardianship Committee and staff.

The Arc New York Corporate Guardianship Program strives to support the growing needs and decision-making choices for hundreds of people with intellectual and developmental disabilities (I/DD) and their families in New York State with the utmost respect and dignity. As a result of changing attitudes about guardianship throughout the United States and internationally, the passage of new legislation on Supported Decision-Making, as well as the implementation of the Guardianship Program's Strategic Plan, The Arc New York and its Chapters have been exploring new and creative approaches to providing the least restrictive supports to individuals receiving services.

We have also provided some demographic information and interesting facts generated by our guardianship database on the people receiving guardianship services.

The Guardianship Program staff are already looking forward to holding an in-person Training Symposium in the Fall of 2024, and strategies to meet the ongoing challenges and person-centered needs and wishes of hundreds of people we support throughout New York State.

It is with gratitude that the Chapters' committee members and staff understand and continue to demonstrate the guiding principles and tenets of the guardianship program. We are very impressed with the spirit, commitment and passion that is exhibited throughout the Chapters on a daily basis.

Thank you

**Respectfully Submitted by:
The Guardianship Program Staff
The Arc New York**

