





2018 Guardianship Supports Survey Results
“What have we learned?”

Preparing for the future.....

- Spring 2018 survey of Arc NY Chapters
- Arc NY Guardianship Committee strategic planning retreat (May 30th & 31st)
- Draft focus statements, updated Mission & Vision statement for Guardianship
- Appointment of Strategic Planning work group
- Draft plan to be presented at November Arc NY Guardianship Committee meeting
- Regional presentations (?)



2

What did the survey tell us?

- Diversity is size of programs, resources available and staffing arrangements
- Similarity in “needs” from Arc NY
- Shifting census due to age, new options and purpose for “decision making”
- Guardianship serves very few individuals in relation to full Arc NY census
- Families and individuals with I/DD desire information, viable supports and comfort for life time protections



3

The Arc New York Guardianship Programs Demographics

- 42 responses – 41 active Guardianship Programs
- 26.15 FTEs
- 299 volunteers

<u>Court Decreed:</u>	<u>Pending Court Decree:</u>
Primary = 354	10
Standby = 149	7
Alternate = 151	3
TOTAL = 654	TOTAL = 20

TOTAL = 674



The Arc New York Guardianship Programs Budget/Spending

Guardianship budget/spending:

\$2,193,500 (NYSARC, Inc. Grant distribution)

\$ 272,526 (fund raising & other sources)

\$2,466,026 TOTAL

Budget range: \$9,000 - \$470,890



Guardianship Services and Supports PRIMARY INDIVIDUALS

DIRECT SERVICES

Visits (average 12.29 visits yearly or "monthly")

PURPOSE: (order of importance)

1. Well-being and Happiness
 2. Advocacy and Quality of Care
 3. Celebrations (social, holiday, birthday)
 4. Medical – Health Care Decisions
 5. Safety
 6. Community activities
 7. Quality of Life
 8. Information gathering/information sharing/observation of care
 9. Meetings
- Education and Information
 - Support Surrogate Court Petitions
 - Other supports for families

DIRECT SUPPORTS (PRIORITY ORDER)

- Health care decisions.....5.00
- End of life planning.....4.75
- Placement decision.....4.73
- Lifelong involvement.....4.70
- Celebrations.....4.68
- Self-Advocacy4.60
- Communications with staff/program.....4.50
- Coordination of care.....4.10
- Community involvement.....4.09
- Social life.....4.00
- Program Planning.....3.95
- Communications with family.....3.92
- Medical appointments.....3.85
- Family involvement.....3.80
- Communications with friends.....3.43




Guardianship Services and Supports STANDBY & ALTERNATE STANDBY INDIVIDUALS

- 24/41 (60%) Chapters visit Standby Guardianship Individuals
- 16/41 (40%) Chapters visit Alternate Standby Individuals

Reasons for visits: (order of responses by count)


1. ISP/Life Plan Meeting
2. Overall care and familiarity with individual
3. Information on supports needed & succession information
4. Assessment of needs
5. Celebrations (social, holiday, birthday)
6. Well-being and happiness
7. Assisting parents/families with questions and future planning
8. Safety



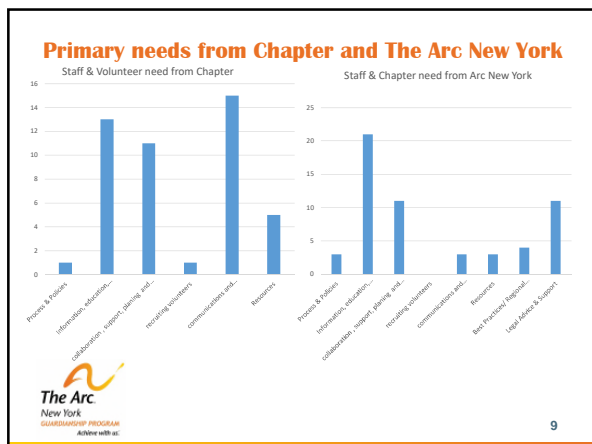
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Some trends and issues to watch...

- Five (5) Chapters turned away guardianship requests in the past year because:
 - Chapter moratorium due to compliance issues
 - Found alternative arrangements / advocates for individuals
 - Individual not involved with Chapter programs
 - Individual already has guardianship and severe mental illness
- Twelve (12) Chapters offering "a la carte" or limited Guardianship
 - Fee for service advocacy program (tailored and limited)
 - Education of families & staff on alternatives (Power Of Attorney and Health Care Proxy)



8



What did we learn.....

<p><i>Needs at the Chapter level:</i></p> <ol style="list-style-type: none"> 1. Communications and information about the person 2. Information, education, guidance and training 3. Collaboration, support, planning and advocacy for the person 4. Resources 	<p><i>Needs at The Arc New York level:</i></p> <ol style="list-style-type: none"> 1. Information, education, guidance and training 2. Collaboration, support, planning and advocacy for the person 3. Legal advice and support 4. Resources
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10

Current practices that ARE effective:

- Annual reporting
- Visits with individuals
- Supports and alternatives to guardianship
- Regional meetings and symposium
- Training and continuing education
- Documentation and recordkeeping
- Incident and Event management
- Conflict of Interest policy
- End of Life support / quality of life support
- Collaboration and oversight of decision making
- Variety of committee members



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Current practices that are NOT effective...

- Self Assessment
- Peer partnering
- Sending ISPs/Life Plans and behavioral support plans with Annual Status Reports
- Meeting quorums
- Annual Status Reports
- Incident and Event reporting process
- Burial plan requirement for application request
- End of life decision making (too complicated)



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So what did we learn from the effective and not effective lists?

SAME LIST!



13

What families want?

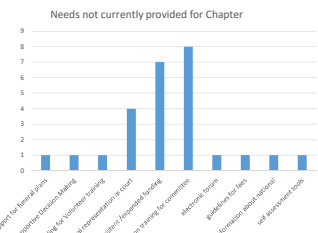
- Viable – sustainable Guardianship Program
- Assistance with Guardianship petitions and reports
- Trainings and information
- Alternatives to Guardianship
- Information and advice on Supplemental Needs Trusts
- End of Life planning / training



14


Areas for New or Expanded Supports from The Arc New York

Needs not currently provided for Chapter

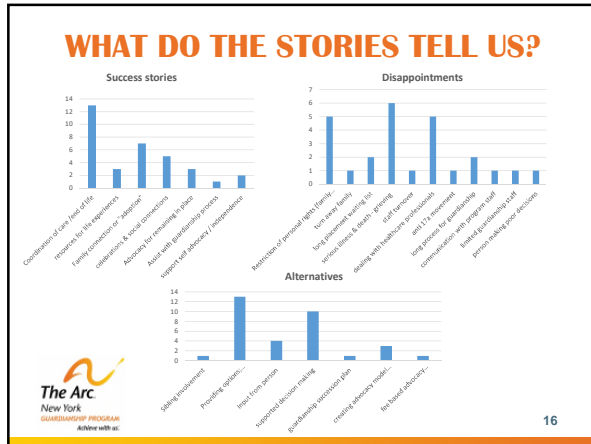


New or expanded needs:

1. In-person training for Chapter committees
2. Consistent and expanded funding
3. Legal representation



15



Take away from the stories...

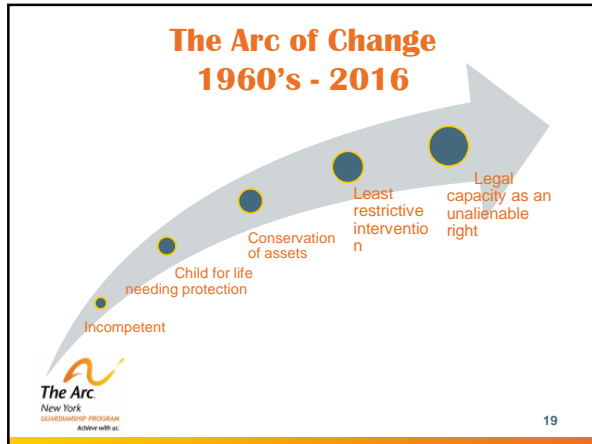
- **Coordination of Care** is the strongest influence in guardianship followed by the family connection and maintaining social connections.
- Guardianship committees struggle with **grieving** at times of significant health conditions and death of the individual.
- **Managing relationships** with the **healthcare** professionals and dealing with **families and staff** who struggle with **control over individual** choices and decisions is difficult for staff and committee members.
- Chapters are providing **options to Guardianship** through the use of healthcare proxies, limited guardianship, supported decision making and boutique advocacy services.

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Top 5 Values of Guardianship

CHOICE
SAFETY
WELLNESS
SECURITY – STABILITY
SELF ADVOCACY

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- Challenges to 17-A Guardianship**
- DRNY Federal Law Suit
 - Governor's Olmstead Report
 - Current standards for supports and practices
 - Advocates and Self Advocates
 - NYSBA
 - Law Revision Commission
- The Arc New York
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- Court Reform Issues that create concern..**
- Appointment of counsel, possibly MHLS
 - Annual reports
 - Rejected petitions
 - Restoration of rights
- The Arc New York
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Not Available in 1969

- Health Care Proxy
- Family Health Care Decisions Act
- Health Care Decisions Act for Persons with Developmental Disabilities
- Available: Power of Attorney
- Supported Decision Making



22

**Emerging (imminent) Issues...
Managed Care**

Care Coordination

- service coordination for people currently MSC
- include coordination of other services, such as health care, wellness, behavioral, and mental health services
- a single individualized Life Plan replace Individualized Service Plan (ISP).

Managed Care

- a health care delivery system organized to manage cost, utilization, and quality.



23

Other Emerging Issues

- 90,000 MSC served individuals go to Care Coordination Organizations
 - Seven (7) Care Coordination organizations
 - Care Coordination "vs." MSC
- "New" people with requests for "guardianship" – (fear of independence)
 - People on the spectrum of autism
 - Behavioral challenges
 - Significant health issues
 - Variety of competencies and limitations

– Council on Quality & Leadership AND The Arc US discussions



24

How do we Frame the conversation about the Future?

- The Person? ...victim or beneficiary of support
- The Services? ...Security and Safety or Well Being
- The System? ...Oversight or facilitated guidance
- The civil rights? ...Protection or Advocacy
- The Resources? ...Limited resources or creative continuum



What is the Emerging Role for “Guardianship”? THE QUESTIONS

The Arc New York serves 60,000 people with I/DD (354/654 in Guardianship)

- What is our relationship with them for advocacy, advice, support, guidance and guardianship?
- Does Arc New York have a role in the lives of all people we support to ensure their ability to access services and supports?
- What are the guiding principles for advice, support, guidance and guardianship in the lives of people we support with varying levels of capacity?



What is the Emerging Role for “Guardianship”? THE QUESTIONS

- What is the role of Arc New York (guardianship or otherwise) with the care coordinator and care coordination organization?
- What public policies and practices should Arc New York advocate to support the majority of the 60,000 people we support to ensure their rights and access to services?
- What is the role of the Arc New York Guardianship Committee, and Chapter guardianship staff?

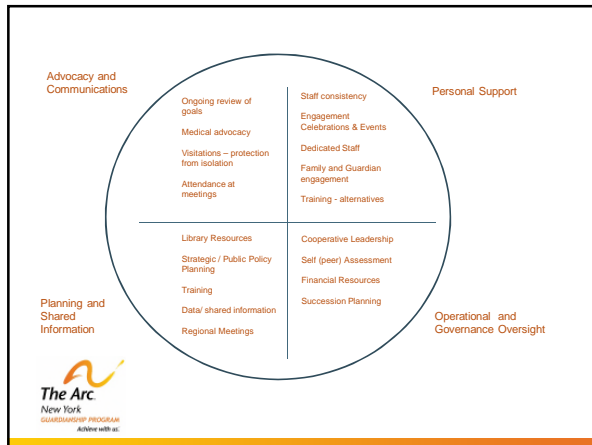


What is the Emerging Role for “Guardianship”?
THE QUESTIONS

- What are the issues related to new legislation for Article 17-A?
 - *(Define advocacy vs. protection)*
- Do we need to “reframe” the issues and questions?
- How does Supported Decision Making and alternate supports relate to Article 17-A discussions?




28



VALUE ALIGNMENTS:

INDIVIDUAL	GUARDIAN/FAMILY	COMMITTEE(S)
COMFORT	CHOICE	RELATIONSHIPS
PROTECTOR	SUPPORTER	CHAMPION (ADVOCATE)
DUTY	DIFFICULTY	CONFLICT
COORDINATION	TRAINING	OVERSIGHT



30

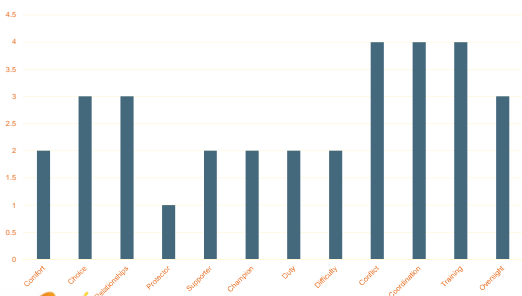
How do we measure success?

RELATIONSHIPS	PLANNING	TECHNICAL SUPPORTS
Staff/Guardian	Celebrations and Events	Wide Attendance at Planning Meetings
Meetings and Engagement in Person's Life	Succession Plan	Technical Assistance and Advocacy
Dedicated Staff	Supportive Chapter Leadership	Resources
Supportive System	Assessment and Review	Strong Planning and Visionary Tools




31

Shared Values



Value	Score
Contact	2.0
Choice	3.0
Relationships	3.0
Freedom	1.0
Support	2.0
Ownership	2.0
Data	2.0
Difficulty	2.0
Control	4.0
Cooperation	4.0
Training	4.0
Demands	3.0



32

Tools (barriers) for Successful support of THE VOICE

INDIVIDUAL:

- Consistency (inconsistency) of services
- Staff Changes
- Ongoing review of goals
- Personal care practices
- Medical Advocacy
- Visitations - protection from isolation



33

Tools (barriers) for Successful support of THE VOICE

FAMILY AND GUARDIANS:

- Attendance at meetings
- Engagement with individual
- Succession planning – life planning alternatives



34

Tools (barriers) for Successful support of THE VOICE

THE ARC NEW YORK GUARDIANSHIP COMMITTEE:

- Training
- Data collection / data analysis
- Regional meetings
- Self assessment – peer review
- Library of resources for chapter and staff
- Strategic planning



35

Tools (barriers) for Successful support of THE VOICE

CHAPTER STAFF AND COMMITTEE:

- Fully dedicated Staff
- Cooperative / interested leadership
- Resources
- Data and shared information
- Education and training on alternatives




36

MISSION

Revised by Guardianship Program Staff August 2018

The Arc New York's Corporate Guardianship Program offers a continuum of services for individuals with intellectual and developmental disabilities who require different levels of advocacy and supports. The Guardianship Program will take into consideration the personal wishes, preferences and beliefs that afford each person the independence and participation in all decisions affecting their lives. The Program further seeks to ensure that the decision-making needs of every person receiving guardianship and alternative supports is addressed in the least restrictive manner while promoting his or her individuality, autonomy, dignity, and self-worth.




37

VISION

Revised by Guardianship Program Staff August 2018

An individual with intellectual and developmental disabilities has their VOICE heard in every life decision.



38

GOAL 1

Personal Support: The individual is ideally supported with consistent advisors, valued personal contacts and events and clear information to guide decisions in all aspects of life.

- Advisors – consistent and informed staff and/or guardians who support events and decisions (**#1 Training**)
- Valued Person Contacts – engaged in goal setting meeting, personal celebrations and opportunities for creating and maintaining friendships and family relationships
- Clear Information to Guide Decisions – tools appropriate to the individual which provide opportunities for decision making related to their life including options and alternatives. (**#12 Brochure**)



39

GOAL 2

Advocacy and Communications: The individual and guardianship support staff/guardians are engaged fully in discussions and review of life goals, medical and social support decisions, plans and participation in events for full personal involvement with family and friends and guaranteed participation in all meetings and decisions as desired.

- Engaged Fully in Discussions and Review of Life Goals – active invitation and involvement of the individual and guardianship support in real conversations which are focused on the desires of the individual
- Plans and Participation in Events - ongoing and actively reviewed calendar of events that relate to the person and their life.
- **Develop an annual system of communications and training for family guardians, guardians and guardianship staff to ensure quality of knowledge and information regarding guardianship issues, alternatives and requirements (#1 Annual Symposium)**
- Guaranteed Participation in All Meetings – every effort made (scheduling options, social media options, full consultation and support by knowledgeable individuals) to include the individual in all meetings and contacts during which decisions are discussed.



40

GOAL 3

Operational & Governance Oversight: The system of guardianship support in the local Chapter and Arc New York informs and evaluates the elements for quality and individual satisfaction.

- Each Chapter ensures that the board and appropriate leadership are fully educated and engaged in oversight and support of guardianship program options for the individuals in the Chapter programs.
- **Develop policies and practices regarding the merging Care Coordination process for managing service and supports for people with IDD (#2 Care Coordinator Policies and Practices)**
- The Chapter regional systems provide active evaluation, support and guidance among the Chapters to support, guide and provide quality guardianship programs. **(#1 Annual Symposium; #8 Regional Meetings)**
- Each Chapter guardianship program creates a plan to educate and assist families for timely succession, when needed, to ensure no lapse in support for the individual.
- Each Chapter and Arc New York engage in providing a financial plan of support for local programs which include support from the Arc New York Trust, engagement with families to provide personal funding and Chapter plans for local resource planning. **(#11 Fee/Pay for Service)**



41

GOAL 4

Planning & Shared Information: Arc New York provides a system plan to ensure that local Chapters, Families and Guardians have access to information and tools for a full continuum of Guardianship supports including, but not limited to, Article 17a, Article 81, Supported Decision Making and Self Advocacy supports and training.

- Build and maintain a library of resources and training supports available in multiple formats, easily accessible and well broadcast to all stakeholders in the Arc New York system. **(#3 Training; #4 Web Forums)**
- Evaluate and create a plan for public policy to support all levels of guardianship supports including but not limited to, legislation supports for Article 17a, Article 81, Supported Decision Making and Self Advocacy supports and training. **(#12 Brochure)**
- Evaluate the system of data collection to enhance usable information for the purpose of supporting public policy initiatives, provided guidance to local Chapters, and evaluate the full engagement and commitments to supporting individuals with developmental disabilities in the pursuit of full engagement in personal life decisions. **(#5 Data Collections; #9 Annual Status Reports; #10 Forms Review; #13 Document Retention)**
- Continue to build and support the use of regional meetings to evaluate, train and support the local Chapters in their guardianship program supports.



42

MEASURED OUTCOMES

The outcomes for measurement should focus on the details listed by the stakeholders as the most important values of the program. These include:

- Building consistent and lasting relationships
- Engagement in the life of the individual at a personal level
- Creating leadership support for the program throughout the entire system
- Building and maintaining tools for communications, training, data collection and assessment
- Communicating a strong public policy program to provide support



43

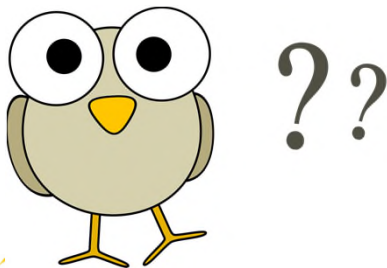
NEXT STEPS

- Responses from the Chapters.....
- Workgroup discussions and recommendations
- Arc NY Guardianship Committee presentation
- Regional presentations
- Strengthening the regional processes (training, self reflection, shared resources, data collection, etc.)



44

Questions?



45
