Advocacy & Protective Services, Inc.c.

Transforming Guardianship

How One Guardianship Agency is Implementing Supported Decision-Making in Ohio

Kristen Henry, APSI Executive Director

Agenda

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- Overview of APSI
- Ohio's Guardianship and I/DD Service Systems
- SDM in Ohio: Opportunities and Challenges
- What APSI is Doing: 5 Case Studies
- Next Steps

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Overview of APSI

APSI's History

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- Ohio's unique private guardianship agency
  - Corporate guardian
- Non-profit organization
- Created in 1983
  - Merger of "community" and "institution" guardianship agencies
- Funded by Ohio Department of Developmental Disabilities
  - Statutes and regulations provide parameters

APSI's Role

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- Consistent mission and service
  - Guardian of the person only
    - Or alternatives to guardianship of the person
  - Adults with I/DD
  - Statewide service
- Change in scope over past decade
  - Guardian of last resort
  - Significantly reduced number of clients
  - Most clients have dual diagnoses (MH/DD) and/or complex medical conditions
- Referrals/requests for service reviewed by APSI staff for acceptance or placement on waitlist
  - Some counties make direct appointments

APSI's Organization

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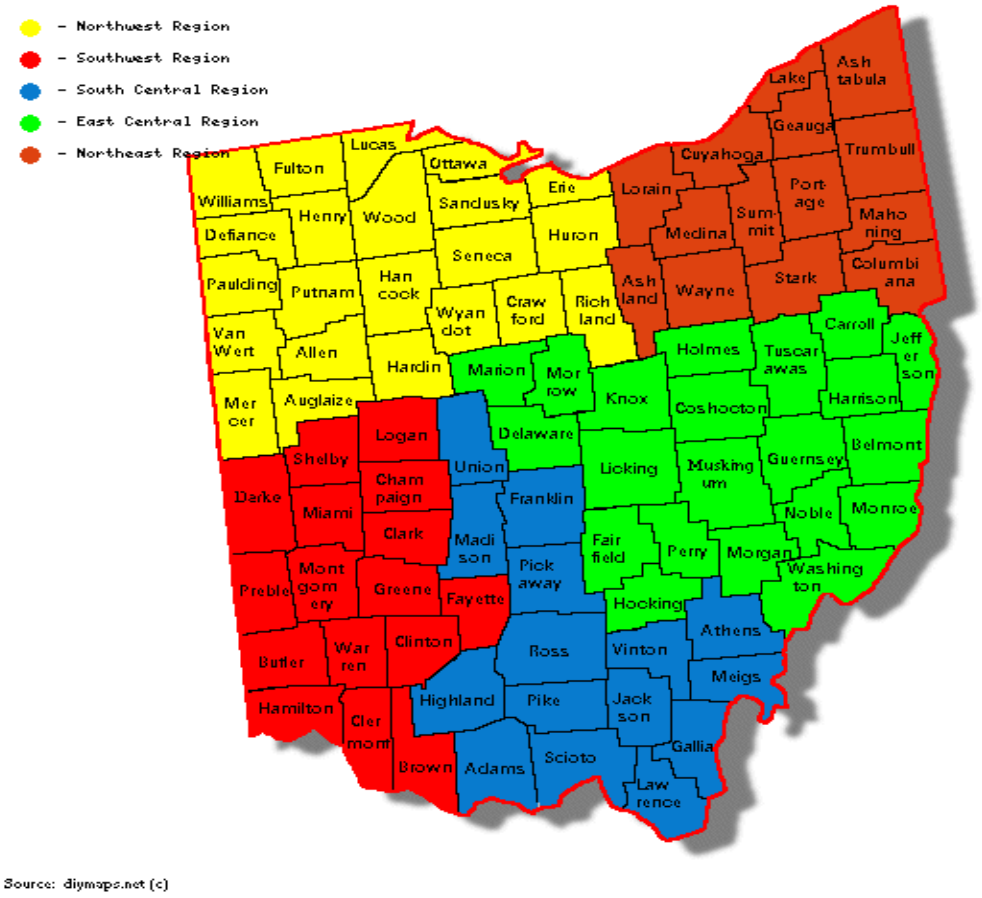
- 9 offices in 5 regions
- 75 PSRs: protective service representatives
  - Average caseload 45-60 individuals
- 6 RPDs: regional program directors
- Medical specialists provide support on complex issues and after hours



Source: diymaps.net (c)

APSI's Numbers: July 2017-June 2018

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- 3,534 clients
- 24,984 in-person visits
- 580 long-term moves
- 7,868 after-hours calls
- 10,178 medical informed consents
- 6,514 service informed consents
- 680,000+ miles traveled
- 12 restorations (18 in FY2019!)

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Ohio's Guardianship and I/DD Service Systems

Ohio's County System

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- Ohio LOVES its county system
- 88 county boards of developmental disabilities
  - Governed by 7-member appointed board
    - Selected by county commissioners (5) and county probate judge (2)
  - Led by superintendent
  - Funded by state, federal, and local dollars
    - Local dollars = property tax levies voted by residents
    - Funding varies widely by county
- 88+ county probate judges
  - Elected to 6-year terms
  - MANY duties including guardianship
    - Some also have juvenile/domestic/general jurisdiction
  - Ohio constitutional age limit (70)

Ohio's I/DD System

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- Cabinet-level office: Ohio Department of Developmental Disabilities
  - Funding streams
  - Rules, regulations, and oversight
  - Statewide policy initiatives
  - Administrative support
  - Delegated Medicaid authority to administer waivers
- County boards manage services
  - Service and Support Administrators (SSA)
  - Locally funded services
  - Waiver match funding (with some exceptions)

Ohio's I/DD System In Transition

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- Different pace in different areas
- Rebalancing institutional and community services
  - 8 state-run developmental centers
  - Private ICFs from 6 to 100+ beds
  - 3 HCBS waiver programs
- Privatizing services to become conflict-free
- Reviewing day services and employment

Ohio's Guardianship System

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- 2017: 47,000+ guardianships statewide
- County probate courts = superior guardian
  - Judges and magistrates
  - Court investigators
- Supreme Court of Ohio
  - WINGS group
  - Civil rules and rules of superintendence
- Columbus Dispatch "Unguarded" series (2014)
  - Exposé on guardianship, highlighted bad actors
  - Led to Rule 66
    - Consideration of less restrictive alternatives
    - Annual reports and plans
    - Complaints reviewed by court

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SDM in Ohio

SDM on the Move

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- Many county boards have become very interested in SDM
  - Collaboration with NRC-SDM
  - Trainings for staff, advocates, and families
  - Often spurred by a local SDM champion
  - Focus on transition-aged youth
- Limited statewide coordination
- Some counties include probate judges in discussions/trainings

SDM Opportunities

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- Decent state laws on guardianship
  - Less restrictive alternatives must be considered
  - Right to counsel and expert evaluation
  - Right to annual review hearing with counsel and evaluation
- Lots of low-hanging fruit
  - Plenty of "easy" restorations due to decades of over-reliance on guardianship
- Culture of advocacy
  - State and local advocacy support

SDM Challenges

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- Disparities in awareness and acceptance of SDM
  - County to county
  - County board to probate court
  - Other professionals
  - Families
  - Theory to practice
- Lack of a tangible alternative/proof of concept
  - Need to generalize non-I/DD methods like POA
- Individuals with limited “natural supports”
- History of using APSI/guardianship to make things "easier"
- Skewed understanding of guardian’s role
- Culture of protection
  - Fear of causing harm, being at fault

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What APSI is Doing

APSI's SDM Principles

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- Involve individual in decisions to the maximum extent possible
- Least restrictive service that is appropriate to the person's needs
- Continuum of services
- No need to hang on to clients who don't need us
- Recognize the lack of natural support for some clients
  - But also embrace the family at its level of involvement and understand people change

APSI's SDM Path

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- Decade of focus on reducing scope
  - Inc. restorations and successors
  - Limiting new cases by priority
- Meeting in November 2017 to explore SDM
  - Focus on individuals
  - Start with "easy" cases
- County board partnerships
  - Collaboratively identify potential for restoration
- Strategic plan re continuum of services
  - Defining and communicating alternatives
- APSI Institute in April 2019
  - Training for APSI staff and external groups

APSI's SDM Continuum

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- Prior to appointment
  - Guardian of last resort flow chart
  - Targeted Decision-Making
- Ongoing guardianship
  - Annual plan section on restoration
  - Empowering self-advocacy
- Restorations
  - Guardianship to Restoration Transition

Case Study: TH & JL

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- Two individuals living in ICFs offered exit waivers
- County board requested that APSI become guardian
- No other identified decision-making needs
  - Disagreement between county board and provider
- Met with JH and JL, offered to be "chosen representative/protector"
  - Defined limited role for team and service plan
- Discussed options and supported during process of choosing whether to accept waiver
- TH declined waiver, JL accepted and chose new residence and provider
  - APSI involvement ended

TH & JL: Reflections

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- Very easily could have become lifelong guardianships
- Connection between residential changes and guardianship
- Shows importance of critical APSI review of requests for service
- Vestiges of APSI as the solution to a misidentified problem

Case Study: J-Lo

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- 55 year old man served by APSI since 1998
- Identified by APSI and county board for restoration
  - Not because he always makes the decisions we would make
- County board facilitated expert evaluation and filed with court
- J-Lo, APSI, county board, and provider testified at hearing
- Judge approved restoration

J-Lo: Reverberations

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- Meeting with judge before hearing
- Self-advocacy by J-Lo
- Testimony by long-time provider
- Specific example of recent self-advocacy
- Consistent positive message
- Positive effects
  - Judge
  - SSA Director: “one of my favorite work experiences” in 13 years
  - J-Lo at APSI Institute

Case Study: JT

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- 28 year old man served by APSI since 2008
- Requested restoration in 2017 then withdrew request at hearing
- Identified by APSI and county board for restoration
- JT expressed concern about losing APSI support
- APSI agreed to remain in voluntary "protectorship" role after restoration
  - Time-limited for 6-12 months

JT: Post Script

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- APSI rep continued monitoring and assisting with advocacy
  - Selection of new provider with housemates (also APSI clients)
- Clear communication about limited role
- Addressing concerns while resisting team (provider) requests to re-establish guardianship services
  - Identifying specific issues
  - Clarifying role of guardian

Case Study: KH

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- 30 year old woman served by APSI since 2010
- Mother was her guardian
  - Not a positive dynamic
  - KH hospitalized, transferred to developmental center
- Relationship between KH and mother improved over time with APSI involved
  - KH moved back in with mother, receives minimal services
- Identified by APSI and county board for likely restoration
  - Mother is also supportive of restoration

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Next Steps

Next Steps for SDM

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- Continued collaboration with counties
- Spreading the message
  - 101/Breadth: to people who haven't heard
  - 201/Depth: building on knowledge and experience
- Using the expertise at NRC-SDM!
- Celebrating and sharing our successes
- Implementing processes and clarifying expectations at APSI
  - SDM leads in each region

Questions?

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My Questions

Advocacy & Protective Services, Inc.

- What do you think?
- What are other guardianship organizations doing?
- How can we create organizational process while remembering that SDM “isn’t a process, it’s a paradigm”?
- What guidance can we give our staff to balance dignity of risk with our responsibility to make decisions in the person’s best interest while we are the guardian?