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Life, Liberty, and the Pursuit of Happiness for People with Developmental Disabilities

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Background

- Focused on New York State guardianship law.
- There are alternatives to guardianship available, but some of them are not yet legal in New York
- Legal guardianship can have a detrimental effect
- Alternatives can bring forward more positive outcomes
- Article 17A guardianship statute has been largely unchanged since 1989
- Loss of rights has shown to have negative mental health outcomes
- Loss of decision-making and self-determination = poor mental health for this population
- The needs of this population too often are not at the forefront or research

Study Aim

This study aimed to identify the motivations for selecting legally defined guardianship or its alternatives and the observed mental health characteristics of the individual thereafter.

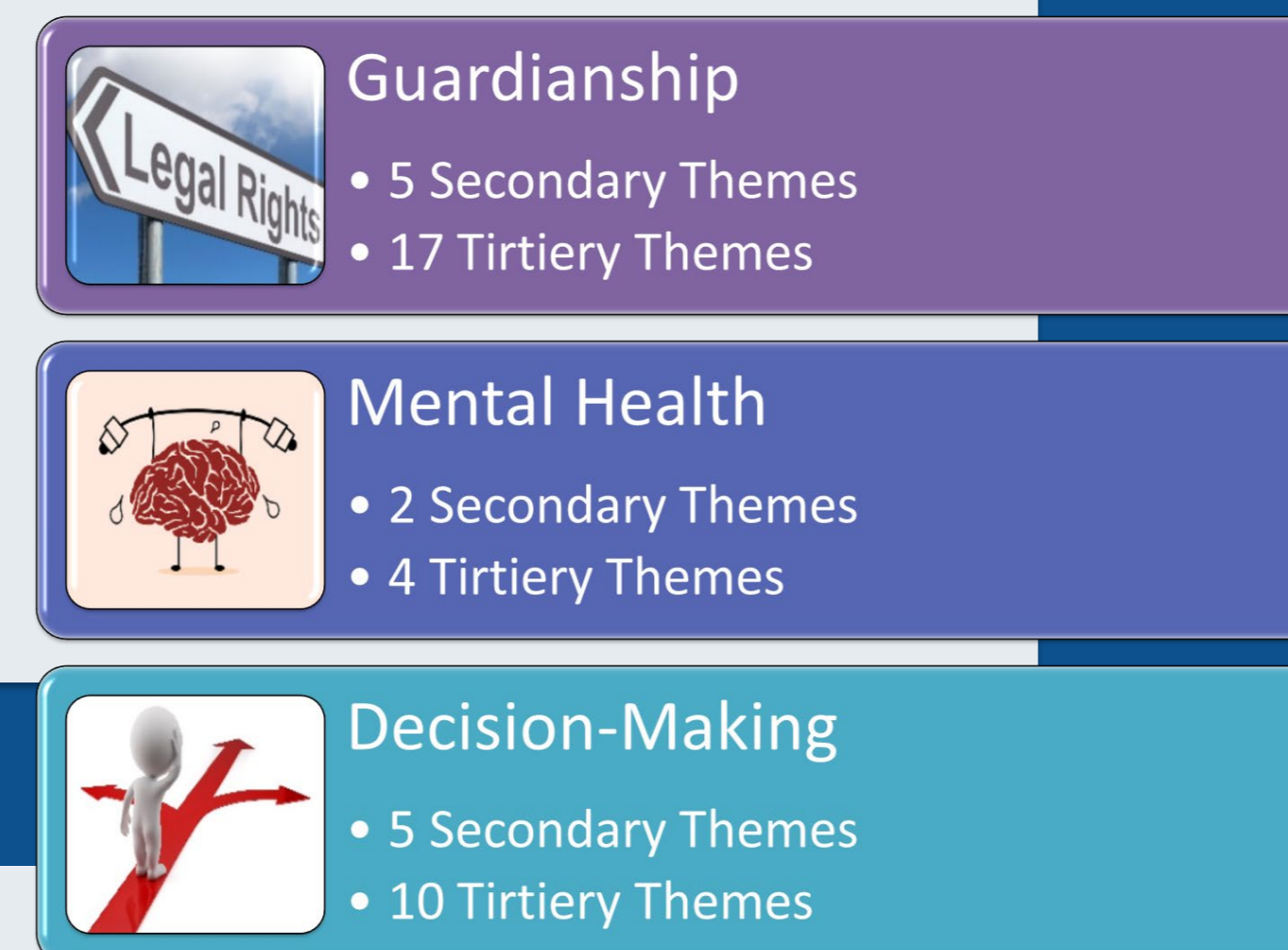
Abstract/Introduction

- As per the 2010 census, there are approximately 1.2 million adults with an intellectual disability and 944,000 adults with other developmental disabilities. There are also 1.7 million children living with an intellectual and/or developmental disability (Brault, 2012). All told, New York State guardianship statute is relatively simplistic and has been unchanged for several decades. Due to this, it can be considered antiquated as the disabilities field is constantly changing. There are various alternatives to guardianship, some of which are not yet legal in New York State, that could greatly benefit the individuals. Social workers and social work educators must be better equipped to share knowledge on guardianship and its alternatives to better supports the millions of people living with intellectual and developmental disabilities. This involves classroom and field education focused on this population, their mental health, and their related services. Additionally, groups focused on self-advocacy for this population require educated facilitators.
- Social workers value the dignity and worth of the person. This fits into supporting the client's right to self-determination; a social worker should support the client in "enhancing their capacity" (NASW, 2017, Ethical Principals Section, para. 4) and supporting them in identifying and addressing their own needs (NASW, 2017). McManus (2006) makes a valid point in stating that, "autonomy and independence do not grow out of being told what to do and when to do it. It is only by having his needs considered, by becoming a participant in the decision-making process, that a [person] develops the capacity for autonomy" (p. 591). As advocates for this population, we should be aware of alternatives to guardianship as well as of the current practices. We must be able to appropriately advocate for our clients and be knowledgeable of options across the field.

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Methods

- Used non-probability volunteer or purposive sampling
 - Snowball sampling was also utilized
- All of the participants must be parents or other advocates for people with intellectual and/or developmental disabilities
- Participants must act in the guardianship role or provide other support as an alternative to guardianship
- Contacted 30+ Provider Agencies, as well as Facebook groups, and private contactors to reach participants
- 11 participants were identified
- Used Zoom-based interviews to collect data
- Data was transcribed using Temi
 - Then imported into QDA Miner Lite for coding
- Used a hierarchical coding method
 - This resulted in primary, secondary, and tertiary themes



Implications/Conclusions

- The results obtained here can impact a better quality of life for individuals
 - mental health, services, and information
- Create shifts in practice
 - schools, case workers, and other practitioners are limited in their own scope of knowledge regarding alternatives to guardianship
- Can influence advocates (parents, social workers, etc.)
- Advancement in understanding of the lack of information
- Social workers should be aware of all alternatives to guardianship
- Highlights gap in knowledge
- Future directions to test or assess novel interventions and prevention methods
- Further research

Results

- Severe lack of knowledge on alternatives to guardianship
- All but four of the participants could not name alternatives to guardianship
- Those who had guardianship felt it was right for their loved one, despite the lack of knowledge.
- Practitioners need to be better informed
- Lack of knowledge of their own rights as guardians
- Individuals were included in decision-making to the best of their abilities
- Learned about guardianship from more than one source
- Noted difficulty navigating the court system
- Did not understand the questions regarding mental health
- Lack of regard to their loved one's mental health needs
- Those who did not hold guardianship had a much keener understanding on their loved one's mental health needs.

References

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