

#### Session Outline

- Typical challenges in working with families of supported individuals
- Understanding why those challenges are to be expected
- Conceptualization of the problem from a systems theory perspective
- Engaging with families why, when and how
- · Case illustrations

## Issues arising when working with families

- When you know there is a problem
- Individuals new to the service system
- Existing individuals with changes in family supports
- Individuals with capacity to give consent vs. individuals who don't have capacity to give consent
- · Examples from experience to illustrate

You know things aren't working collaboratively when...

#### The "good parent"

- Definition: The idea that by virtue of providing residential supports, staff know the individual better than the family members or know what is in his/her best interests better than family
  - We're with her every day so...
  - They don't understand because they don't know him as well as we do

#### The blame game

- When staff and families attribute changes in the individual's behaviour to the incompetence of the other party
  - Whenever she comes back from a weekend over there...
  - That never happens when he is at home with us

#### Circle the wagons

 When staff feel that they are under constant scrutiny and criticism of family members and may react by taking a defensive posture in communication and documentation

#### Shut them out

- When such an impasse has been reached where staff wish to cease contact with family members
  - Only the manager has contact with the family member
  - Communication only happens through a 3rd party
  - Staff entertain the idea of trying to get guardianship of individual reviewed/revoked

#### Why challenges are to be expected

- Multiple positions of authority: Who's in charge?
- Different ways of doing business: Clash of the systems

#### Who's In Charge?

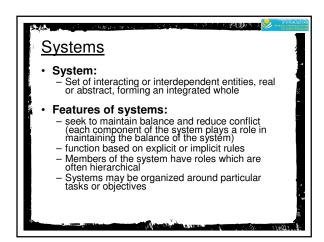
- MCSS
- Doctor
- · Manager, supervisor, ED
- · Parent or guardian
- Other family members (not guardians)
- · Individual being supported

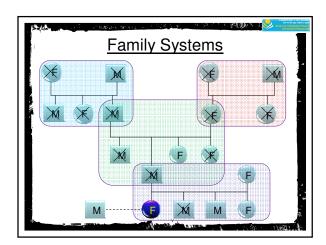
So... Who ultimately IS in Charge re: the individual supported?

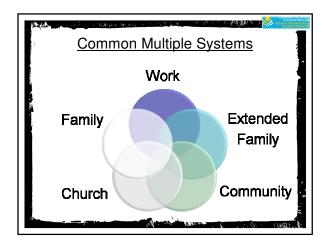
The consent source: The individual or his/her legal guardian

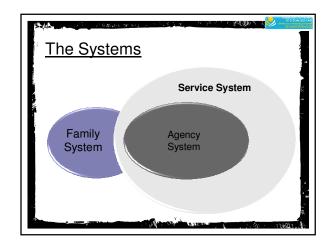
#### Consent

- The Consent Act for physical and mental health-related services
- Bill 77 has nothing to say about consent
- Does the law mandate obtaining informed consent in terms of residential/personal supports?
- Regardless, adopting a model of obtaining informed consent from capable individuals or their guardians is an effective practice









### The Clash of the Systems

- When two or more systems intersect or overlap
- The rules and roles that govern each system may not always correspond
- The leaders of each respective system may believe they have authority in the intersecting system
- · Challenges are bound to occur!

#### Proposed Solution: Joining Teams

- Engagement welcoming the family into your system respecting their role in the family system
- · Open communication
- Transparency
- Respect

## Introducing... Marc Simpson, MSW, RSW Mental Health Centre Penetanguishene

#### **Honouring Family Wisdom**

- Believing in possibilities and building on family resourcefulness
- Working in partnership with families and fitting services to them
- Engaging in empowering processes and making our work more accountable to clients

(Madsen, 2009)

#### **Build on Family Strengths**

- If the individual wishes, encourage family involvement in many aspects of planning and care
- Develop approaches to encourage family involvement

#### **Enhanced Consistency**

- Collaborating with the individual and his/her family in the development of a Person Centered Plan (or in clinical settings the "treatment" plan) improves preferred outcomes
- Consistent supportive approaches are offered by family and support staff

#### How we come to decisions

- Creating a collaborative atmosphere allows room for cohesive decision making
- Service providers must be transparent: No hidden agendas. Determining goals and defining roles and expectations from a "not-knowing" perspective . . .
- An impartial facilitator can aid in the decision making (e.g., case manager)

#### Collaborating with Families

- A collaborative approach must be the default approach. Collaboration needs to begin before tough decisions need to be made
- Collaboration between the service provider and the individual is paramount
- But so to is collaboration with the individual's Microsystems (family, friends, peer group).

#### Collaboration

- Service providers must become aware of their own "philosophy of care"
- Service providers must become aware of the influences of agency culture, community culture and other Macrosystem influences
- Service providers must familiarise themselves with operational policy and procedures (what are the rules!)

#### Collaboration

- Meaningful PCP's
- Identification of goals and desired outcomes
- Designation of roles who does what, how and when
- Ways to enhance communication:
  - Inviting communication and involvement
  - Regular meetings
  - Maintaining focus on individual's needs and goals
  - Maintaining flexibility in our system

#### How Do We Collaborate?

- · Focus on goals and outcomes
- Differentiate roles and responsibilities (be transparent)
- Identify what the family CAN do instead of what you don't want them to do

#### How Do We Collaborate?

- Enhance quality of communication
- Increase opportunities for communication
- Be realistic Can't <u>always</u> align with the family, nor should you. The individual may need you to align with them to support them in enforcing their own wishes (However, be aware of the power of your own or agency's agenda)

#### <u>Increasing Opportunities for</u> Communication/Collaboration

- Inviting communication
- Different forms of communication (email, letter writing, etc – must be aware of agency policy and procedures)
- Expect communication (create a culture of family involvement)

#### <u>Increasing Opportunities for</u> Communication/Collaboration

- Regular meetings
- · Format, goals, etc...

#### <u>Increasing Opportunities for</u> <u>Communication/Collaboration</u>

- Focus on individual's needs and goals primarily
- Then focus on family's goals
- Take a supportive approach even when there are differences between the individual's goals and the family goals

## Increasing Opportunities for Communication/Collaboration

Flexibility in accommodating family's goals and wishes

#### <u>Increasing Opportunities for</u> Communication/Collaboration

 PCP as a living document – regularly updated as needed rather than once yearly – expect and hope for family attendance

#### Case Illustration - John

- 18 year old male recent move from family home to fully staffed group home
- Moderate intellectual disability, cerebral palsy, and past diagnosis of ADHD
- · Parents substitute decision makers in all areas
- Parents tour new home with staffing team and agree for John to move there
- Due to operational issues within agency, John is unable to move into originally planned home

#### Case Illustration - John (cont'd)

#### Scenario #1

- John's family notified by uninvolved and unfamiliar staff
- Referred to director when questions posed by parents no response – only returns call after ED and case manager contacted
- Director gives matter of fact explanation and assurances and parents reluctantly consent to move to different home
- Plans on moving day fall through, parents request meeting with no response
- Redirected back to group home staff by director
- Group home staff administer meds not consented to by parents
- Parents escalate concern to ministry and ED level, demanding move to different group home

#### Case Illustration - John (cont'd)

#### Scenario #2

- Staff meeting held supervisors were informed about decision and provided a comprehensive explanation of why the changes had to be made
- John and his family were informed of the changes by a director who had developed a relationship with family; all questions were able to be addressed
- Rather than taking "a-matter-of-fact, end-of-story" position, the family was invited to consider the information and consult with John's case manger
- The family was invited to call the Director at any time with questions, since the supervisor was away
- The family was made aware of John's adjustment into the new home – including his difficulty sleeping. His mother attended a doctor's appointment and consented to the use of a sleeping aid.

# Summary Families are integral parts of the team in supporting individuals with intellectual disability Family systems don't work in the same way as our system, so challenges are bound to occur but can be resolved When families are the substitute decision makers, they must be consulted to provide consent

