

**Complex Care In
A Complex
System:
Towards Getting
What Is Needed**



Complexity

- Not just # of health/disability conditions or issues
- Includes
 - Mental health issues
 - Socio-economic factors
 - Other challenges

(Loeb, Binswanger, Candrian, & Bayliss, 2015)

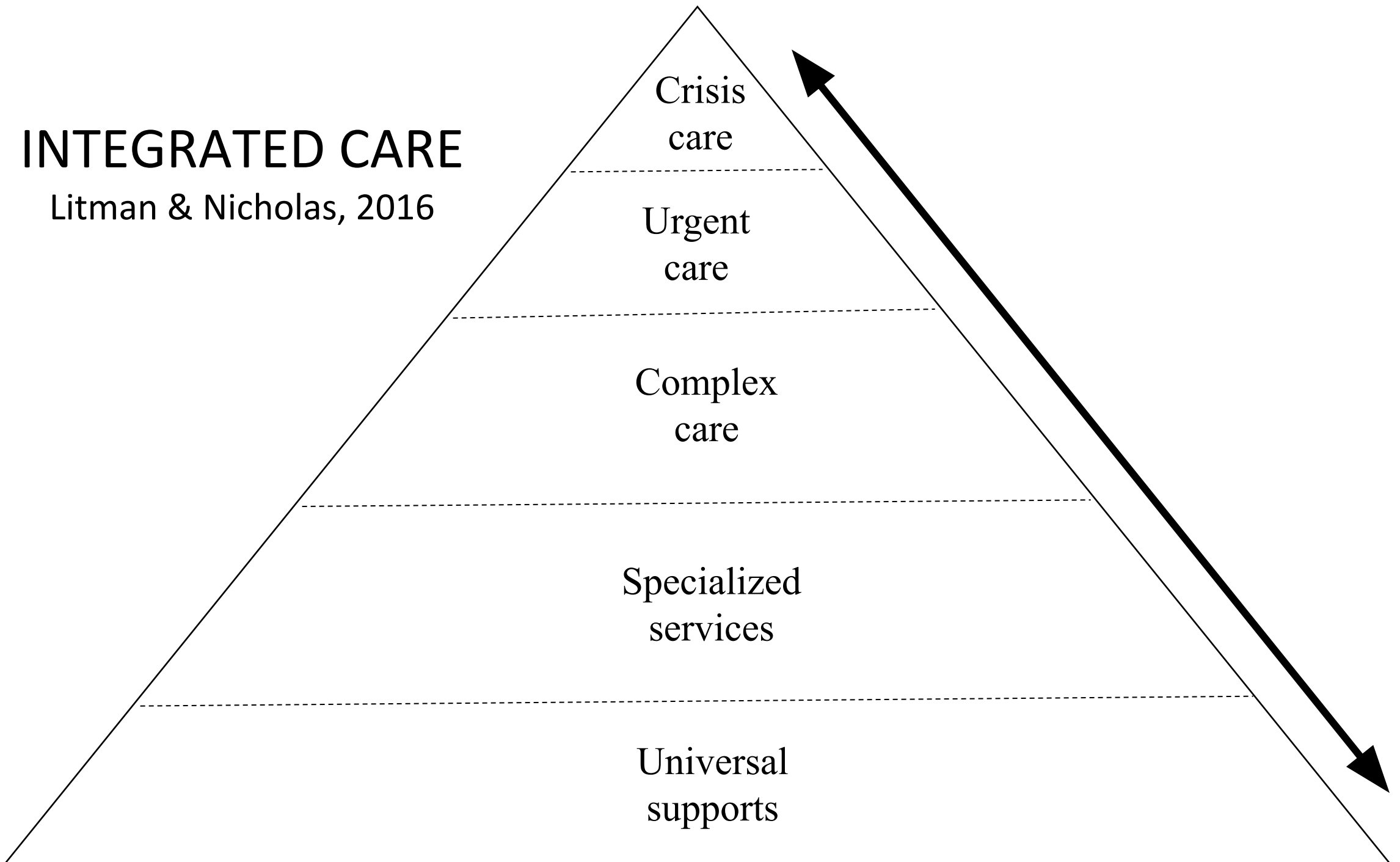
Multi-layered Approaches/Issues

- Minnesota Complexity Assessment Method
 - Illness (medical and mental health)
 - Readiness to engage
 - Social
 - Health system
 - Resources for care

(Peek et al, 2009)

INTEGRATED CARE

Litman & Nicholas, 2016



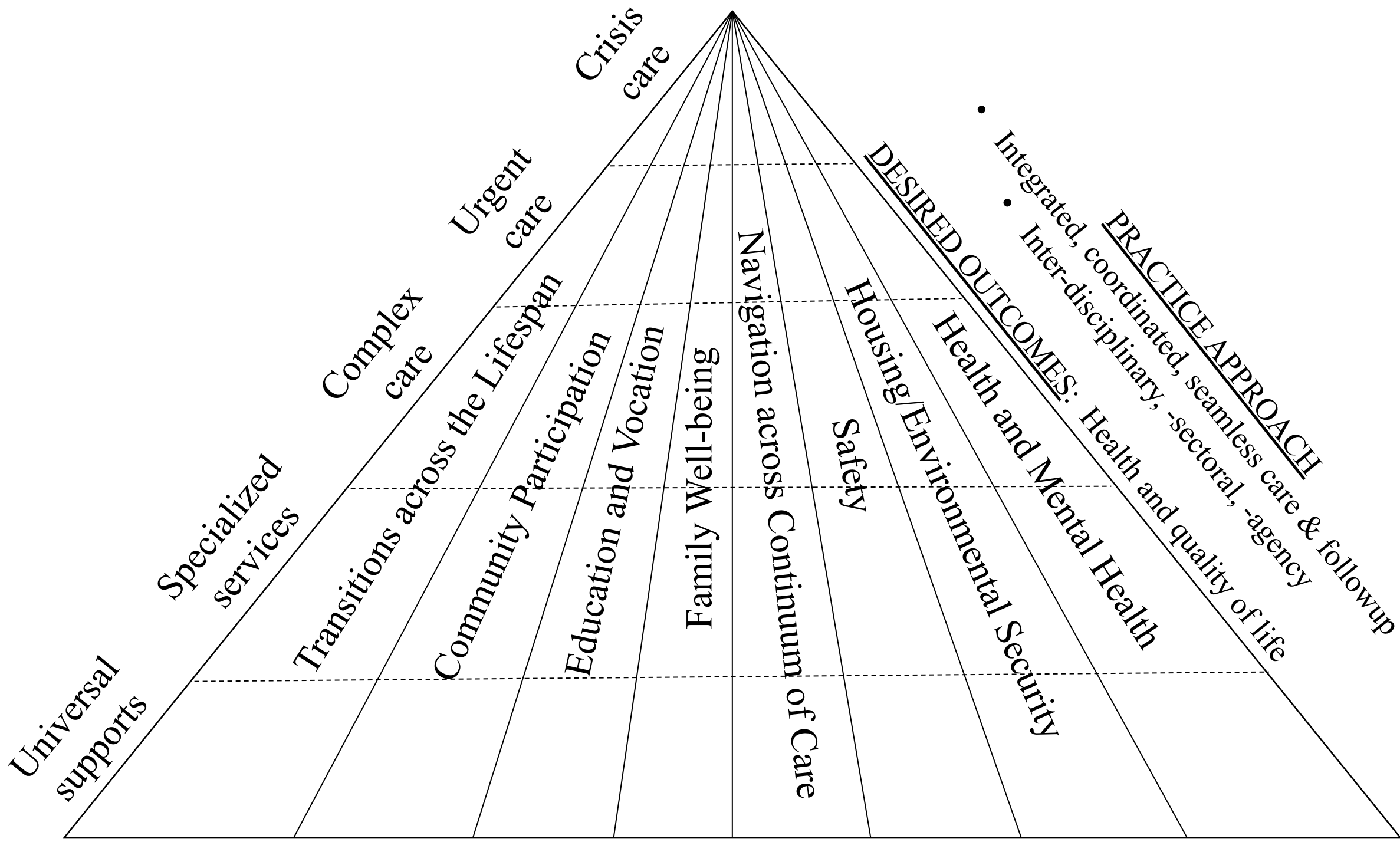
Crisis
care

Urgent
care

Complex
care

Specialized
services

Universal
supports



Mental Health Complexity

Katelyn Lowe

Sinneave Family Foundation

Mental health and complexity

1. The topic of mental health is complex...
2. Getting a diagnosis is complex...
3. Understanding prevalence is complex...
4. Treatment is complex...

Simple things should be simple, complex things
should be possible.

(Alan Kay)

The topic of mental health is complex...

...and still stigmatized and scary

- Talking about mental illness isn't comfortable for most people
- Clinicians don't feel "qualified" to work with autistic clients

Getting a diagnosis is complex...

... and expensive

- Ticking the boxes to see if you are in the box
- Behaviours don't fit neatly into boxes

Understanding prevalence is complex...

...and we need to do better

- Standardized assessments not validated with autistic population
- Most clinical assessments/diagnosis relies on verbal self-report or parent report
- Intellectual impairment and social communication challenges

Co-occurring mental health/psychiatric conditions (CMHCs)

70% of autistic individuals have **at least one** co-occurring mental health condition

40% have two or more

Suicide risk is 4-5 times higher in ASD

- ADHD (33%)
- Anxiety disorders (23%)
- Sleep-wake disorders (13%)
- Depressive disorders (12%)
- Obsessive-compulsive disorder (10%)
- Impulse-control/conduct disorders (10%)
- Schizophrenia spectrum disorders (5%)
- Bipolar disorders (5%)

Treatment is complex...

...and possible

- Modifications and accommodations are often simple (think about employment)
- Common language matters
- Client-centered **and** client-supported

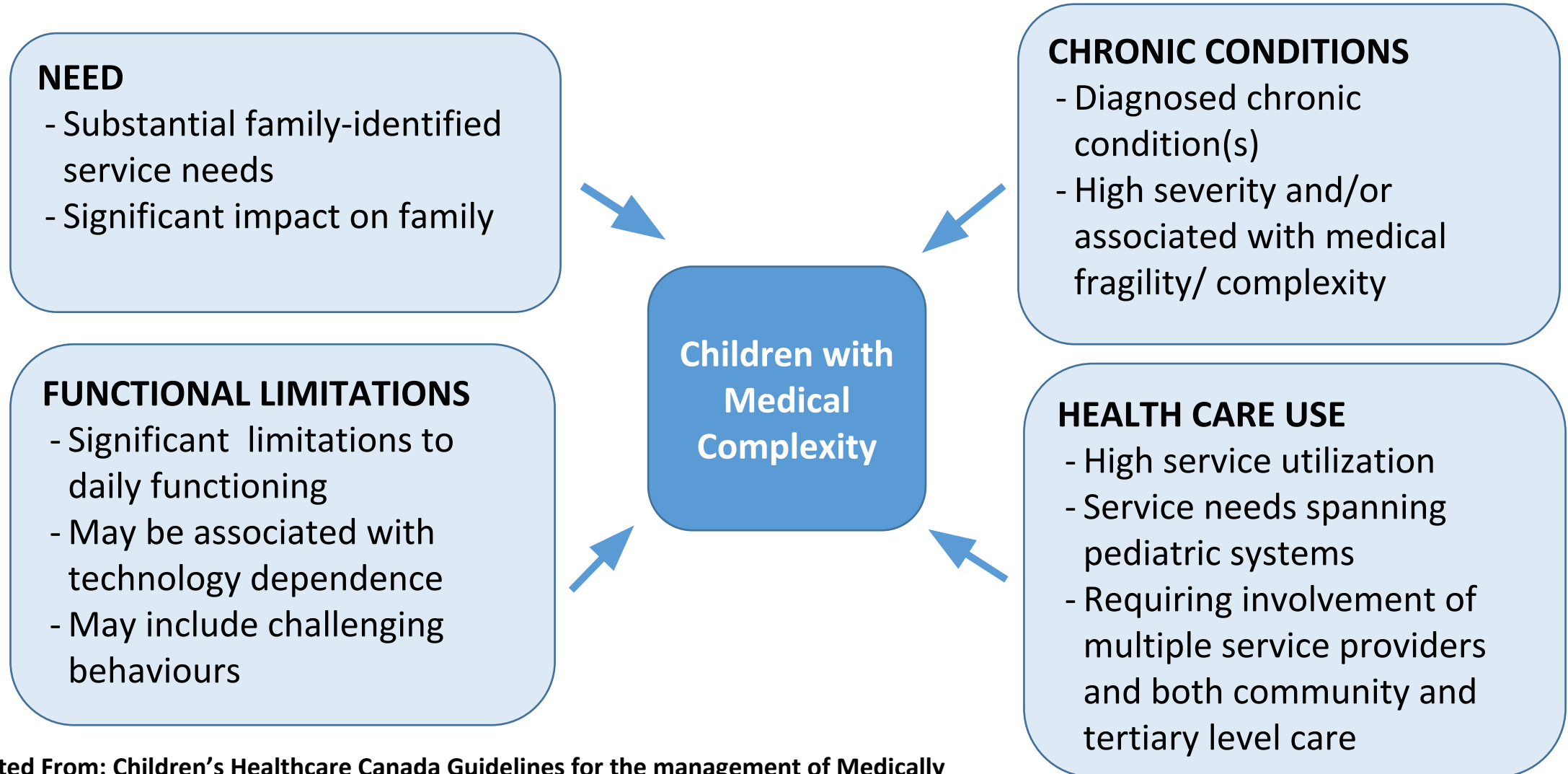
Some good news

- Exclusion criteria in AHS is changing
- Federal Funding for Autism Mental Health Promotion Program
 - Mental Health Literacy, ACT and virtual mindfulness
- Self-advocacy networks, panels, blogs, pride day (June 18)
- Improving outcomes in employment, education, social and recreational engagement also have mental health benefits
- York University – Centre for Autism Wellness Research
 - Thriving not surviving

Medical Complexity

Nadine Gall

Defining Medical Complexity



Adapted From: Children's Healthcare Canada Guidelines for the management of Medically Complex Children and Youth Through the Continuum of Care, 2018

“Autism seldom walks alone” – Jonathan Weiss

Autism is often associated with other concurrent medical diagnoses:

- Epilepsy (20-30%)
- Mental health conditions (50-70%)
- GI conditions / symptoms (45-70%)
- Other developmental conditions and NDDs (e.g., ADHD)
- Genetic conditions
- Behavioural disorders

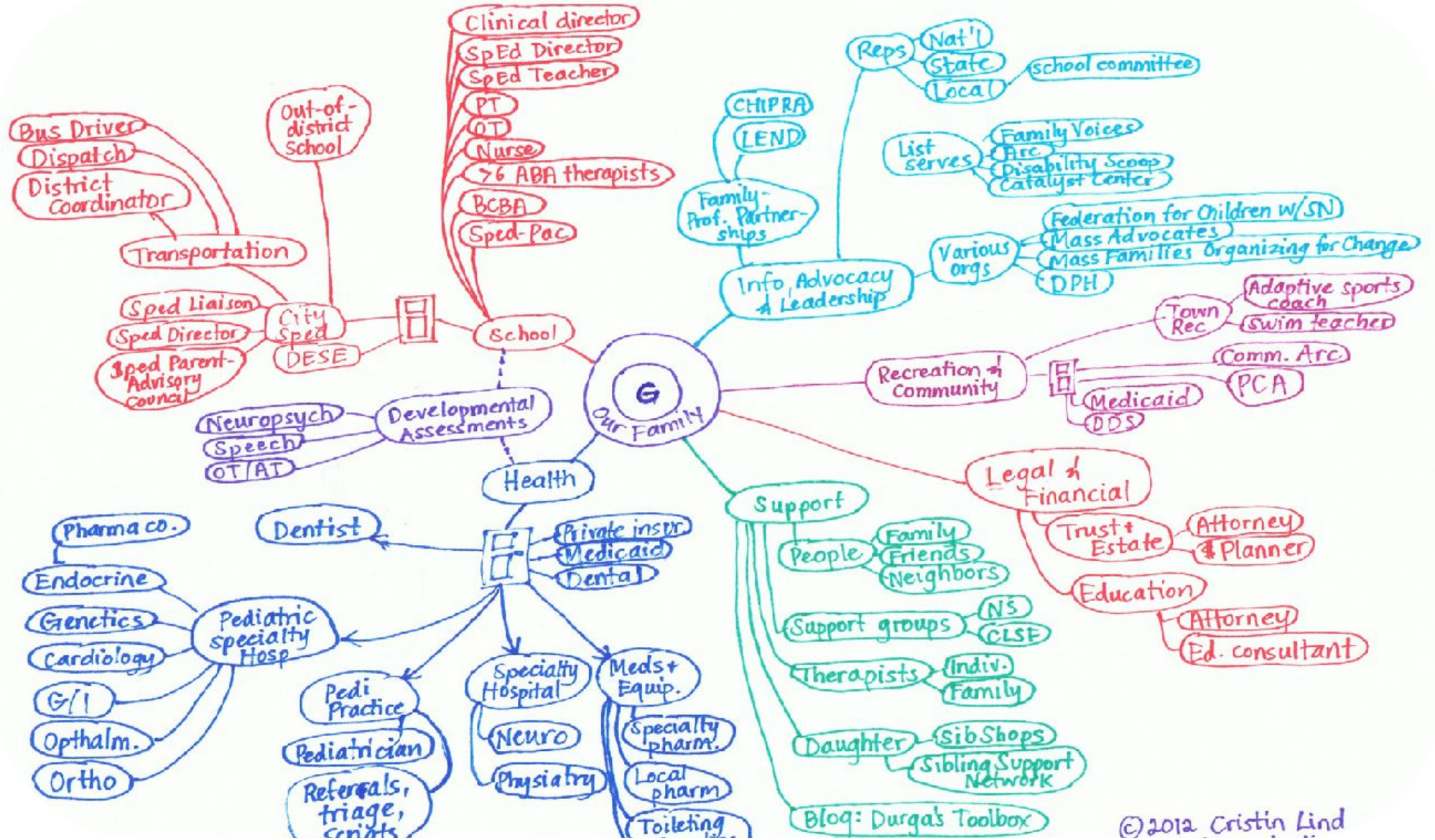
Caregivers of children with ASD and medical complexity may face:

- Declining health
- Mental health challenges
- Higher financial costs
- Lower quality of life
- Higher rates of poverty

“The troubling reality is that adequate services for many families are often put into place only after crises occur and families are overwhelmed”

- E. Ono et al, 2019

Care Team (40+ Professionals)



Family-Centred Care Coordination

Addresses interrelated medical, social, behavioural, education, and financial needs, while enhancing the self-management capabilities of families

(Antonelli et al., 2014).



Examples of ASD Related Initiatives

- **Navigational Supports:**

- Machine learning technology to help families navigate complex health system and connect to targeted community resources and supports
- System navigators

- **Formal Collaboration Across Systems:**

- intentional collaboration across pediatric sectors (health, education, social and community services)

- **Specialized Programming:**

- Partnerships creating more access to specialized programming for individuals with ASD – e.g., Facing Your Fears, Circle of Security, Positive Behaviour Therapy

- **Mental Health Supports:**

- Reducing barriers and better access to mental health supports

Complexity as a Function of emotional dysregulation and/or Symptom Severity

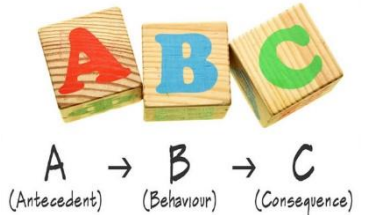
Kim Ward



The term “complex” is often used when:

1. The underlying function of the behaviour is unclear (can't get a handle on “why”)

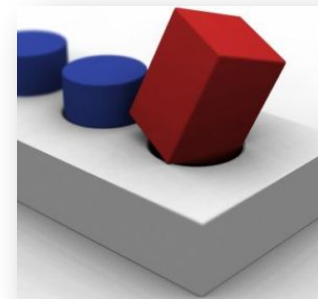
- With ASD the “why” is often related to communication, but not always
- Without the “why” it is difficult to develop an intervention plan
- Factors to consider: medical, mental health, attachment issues, trauma



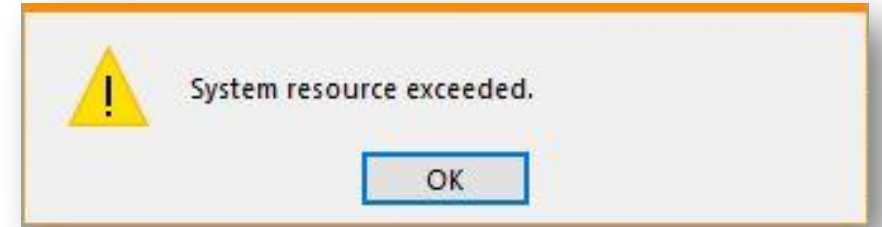
Complexity.....

2. When the profile is not consistent with the ASD “norm”

- Severe aggression/self injury in relatively young children or those without ID
- Preoccupations that put individual at risk
- Life threatening PICA
- ASD in older population



Complexity.....

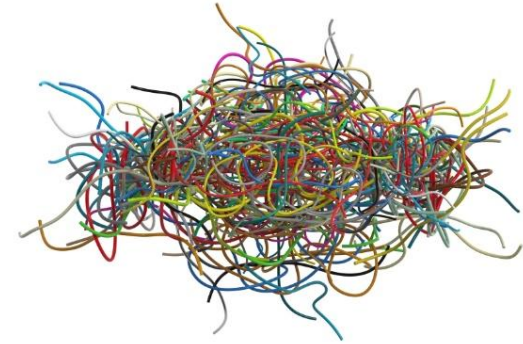


3. When the capacity of existing services/systems is exceeded

- Families - unfortunate progression from in-home to out-of-home supports
- Schools – inclusive classroom to specialized setting to home supported leave
- Emergency or inpatient admission is often utilized at “last resort”
- Less support/services for rural families, ELL families, new Canadians

Observations from Community Clinician

- We are seeing more individuals with complex profiles than in the past
- The complexities are *more complex*
- Complexity often prompts systems and services to evolve and adapt
 - Sustainability is often a challenge due to \$\$



Addressing Complexity –

- Creative partnerships/collaborations
 - CBE Stabilization Class
 - Partnering with other service providers
 - Collaborating with AHS to transition youth out of hospital
 - Collaborating with Arnika Centre Psychiatrists
- Capacity Building
 - Training to deliver Facing Your Fears in the community



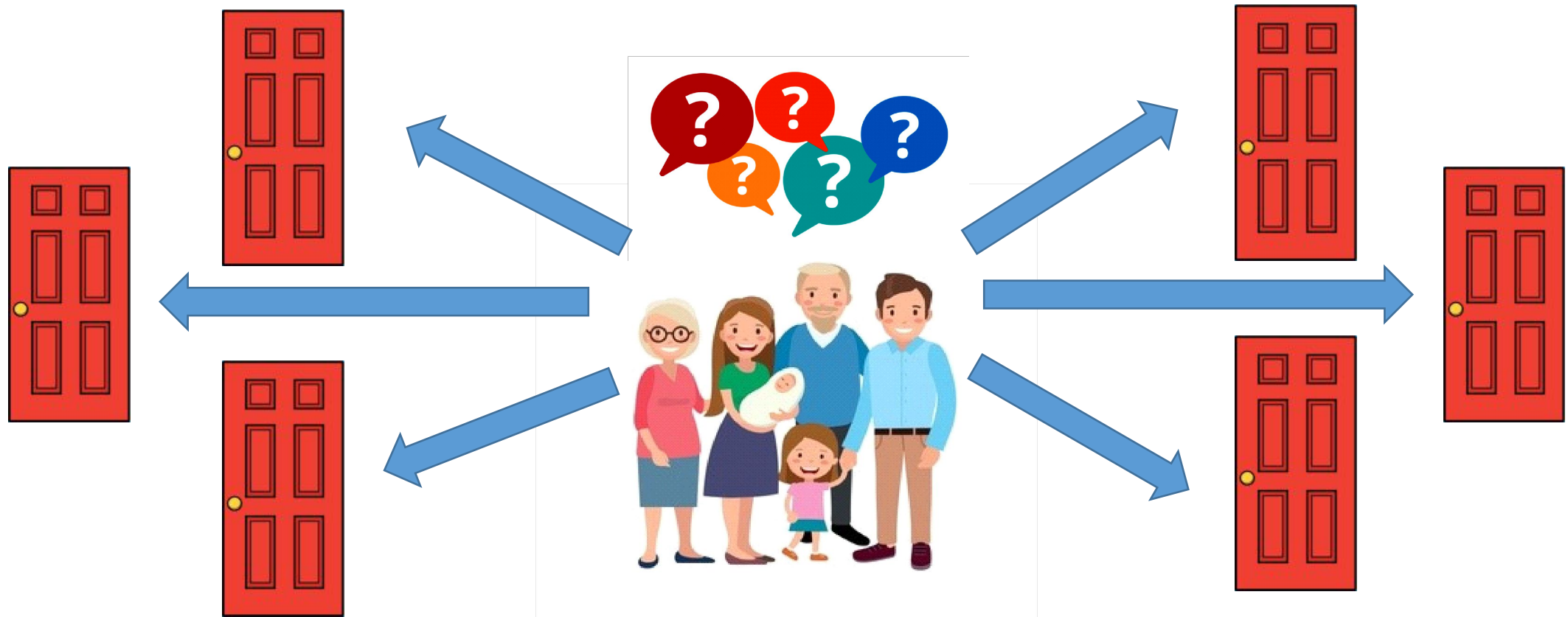
System Complexity

Clayton Kleparchuk

“What is a system? It is a collection of parts that are connected, compatible with one another, interdependent, predictable, and that function together for a common goal or purpose”

- Todd Leader, 2016

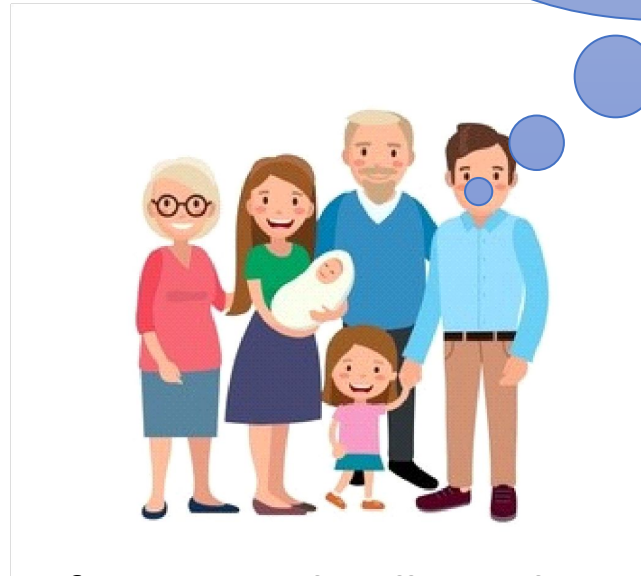
What about people requiring concurrent support from multiple systems?



A System of Systems...

Multi-System Complexities

- Difficult to access and navigate
- Differing mandates/eligibility challenge coordination and alignment
- Gaps and transitions causing lapses in service
- Resource intensive



“I don’t know where to go”
“What do you mean this isn’t the right place?”
“How many times do I have to repeat my story?”
“I don’t agree with you?”
“Why can’t you just keep supporting us?”
“What do you mean by ‘this is a complex situation’?”

There is a growing pressure for improved well-coordinated and seamless transitions of care between different providers, locations and levels of care

Future Steps – It's Not About Us

"One Door"

- Systems moving toward centralized points of access that can support system navigation

Lifespan Models

- Approach that removes age specific milestones that can create arbitrary gaps within and amongst services

System Integration

- Multi-stakeholder collaborations that develop shared accountabilities, processes and goals

"Nothing about us without us"

- Involving people impacted by and/or with lived experience in service planning and policy development

Social Determinants of Health (David)

- Individual, social and economic factors
 - Relate to one's location in society
 - Disability
 - Food security/housing/Income
 - Education
 - Employment/job security
 - Discrimination, racism
 - Early childhood development
 - Trauma
- (Mikkonen & Raphael, 2010)

Some Considerations in Moving Forward...

- Access and Coordination of services
 - Provincial/regional integration and planning
 - Coordinated entry points and connections
 - Case management particularly for persons with complex needs
 - Streamlined processes: continuity of care and avoidance of system blockage
- Inter-agency and cross-ministerial connection
- Development of standards/guidelines: range and flow of services
- Continuum of services, with individualized care planning and support
- Follow-up, with flexibility as needed
- Training
- “Nothing about us, without us”

- Human rights and opportunities

What is our vision for
Alberta?





diagnosis

navigation rights

potential flourish

well-being justice

inclusion autism

relationships

cooperation advocate people

dignity SDOH quality support

spectrum

diversity

- History of public challenges
 - Diagnostic access
 - Service access
 - Limited funding structures
 - Support to families
- Stakeholder engagement
- Reflection and appraisal
- Priority setting: pressing needs, stakeholders
- Move to action, reflection, evaluation...



For discussion at your table

1. Other areas of “complexity” beyond what has been presented
2. Examples of “good work” (that has addressed complexity)
3. Positive steps that the Alliance could take to help address complex care (helping children, youth, adults and families get what they need)