

**MEET THE NEED NC**  
Changing the I/DD landscape across the state

**HEAR. SHARE. ACT.**

## **I/DD and the School System:**

*Making the Case for*

**Building the Foundation for Successful Community Inclusion**

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**DI.**  
**LENS** Lived Experience  
Network Speaks

**LAND**

*Leadership Alliance for  
Neurodevelopmental  
Disabilities*

# MEET THE NEED NC

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Meet the Need NC  
Learning Community

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Lived Experience  
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Meet the Need NC  
Advisory Collaborative

Broader Community  
at Large

## Our Common Agenda

Meet the service and support needs  
of the I/DD Community in NC

WE ARE  
ALL  
HERE





# Where are we Now?





Systemic change for I/DD community services and supports requires a common agenda.


Where are we now regarding Unmet Needs for North Carolina's I/DD community?

 People with lived experience are key to our efforts.

 It is hard to find, keep and know how to best use services.

 People of all ages with I/DD and their families are surviving, not thriving.


 Many changes are going on with Medicaid: Medicaid Transformation & Expansion, 1915(j), and Care Management.

 Many people who need support are not getting it or don't know what help is available.

 The Registry of Unmet Needs (RUN) is **17,000 and growing**; Waiver slots are not.

 Community living and inclusive employment are not realities for people with I/DD.

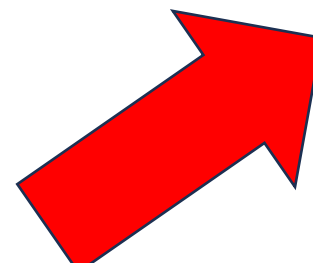
 People don't always agree on what's best for people with I/DD and community living.

 Schools are not preparing those with I/DD for living their most successful lives.

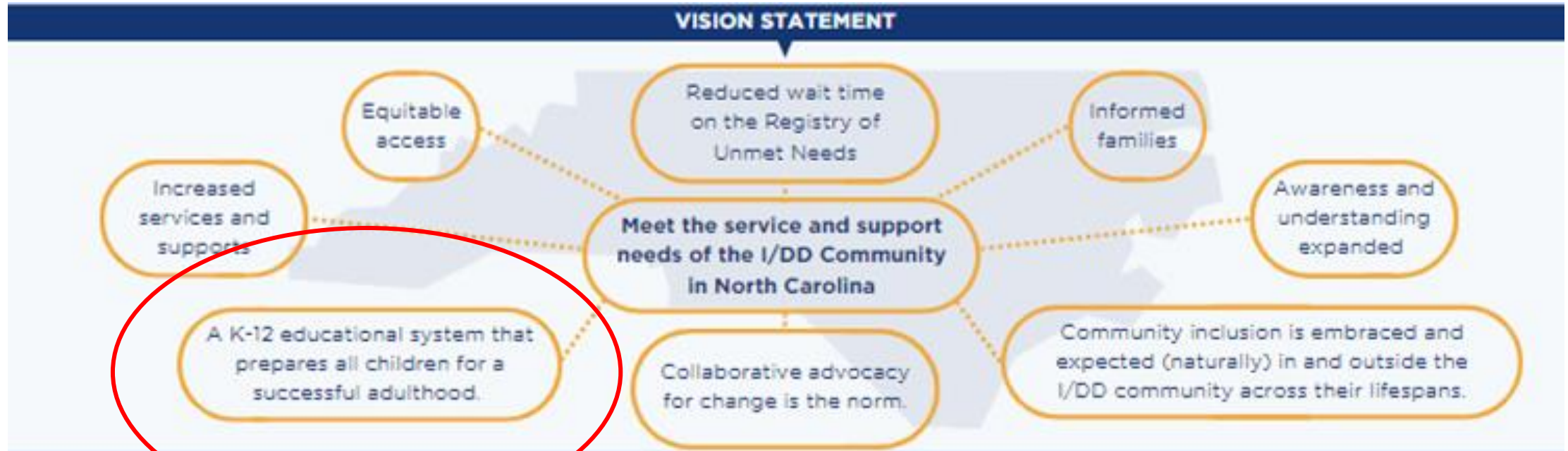
 We are in silos.

The terms Registry of Unmet Needs (RUN) or Registry refer to the waitlist of the Medicaid Innovations Waiver.

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[Common Agenda: 11in x 8.5 in 2023 Meet the Need NC Infographic](#)



# Vision Outcomes

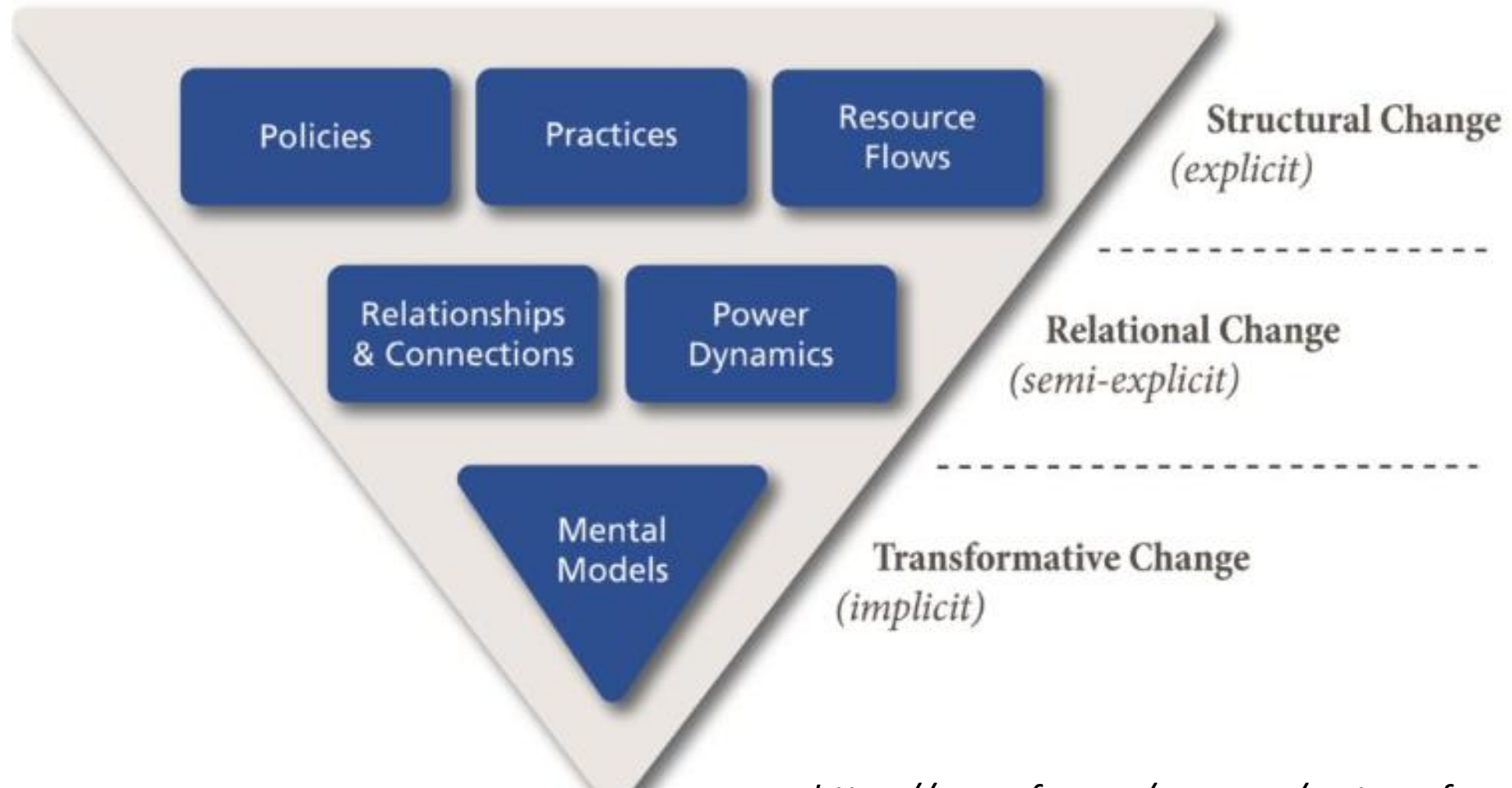


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# Turning a LENS on **System Change** for our I/DD Community

“Systems change is about advancing equity by shifting the conditions that hold a problem in place.”

## Six Conditions of Systems Change



# System Change Conditions - Definitions

*[https://www.fsg.org/resource/water\\_of\\_systems\\_change/](https://www.fsg.org/resource/water_of_systems_change/)*

**Policies:** Government, institutional and organizational rules, regulations, and priorities that guide the entity's own and others' actions.

**Practices:** Espoused activities of institutions, coalitions, networks, and other entities targeted to improving social and environmental progress. Also, within the entity, the procedures, guidelines, or informal shared habits that comprise their work.

**Resource Flows:** How money, people, knowledge, information, and other assets such as infrastructure are allocated and distributed.

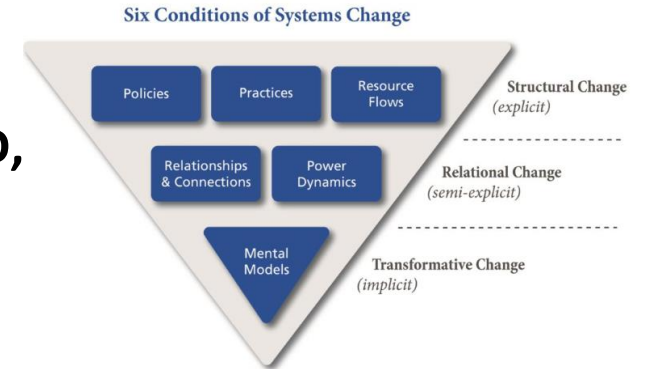
**Relationships & Connections:** Quality of connections and communication occurring among actors in the system, especially among those with differing histories and viewpoints.

**Power Dynamics:** The distribution of decision-making power, authority, and both formal and informal influence among individuals and organizations.

**Mental Models:** Habits of thought—deeply held beliefs and assumptions and taken-for-granted ways of operating that influence how we think, what we do, and how we talk.

# Setting the Foundation for Community Inclusion: Educate

- **If the end game is Community Inclusion at any level for those with I/DD, start the conversations with parents and individuals earlier**
  - All touch points for child must be better I/DD informed at every life stage
  - No “one size fits all” for Community Inclusion – Person driven
- **What are your hopes and dreams for your children? Begin with potential scenarios inclusive in mind at all times of transition**
  - Is your child on the Innovations Waiver waiting list?
  - Do you have private insurance or Medicaid?
  - What assessments are need for services?
  - What services and supports are needed for adulthood?
  - Know the choices for living: community living, ICF, etc.
  - Explore the choices for working?: Dream outside the current “box”



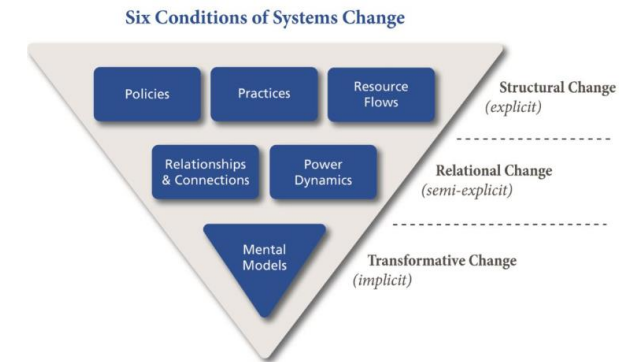
# Setting the Foundation for Community Inclusion: Changing Attitudes

## Our Hypothesis

Changing attitudes *and* being better informed around community inclusion earlier in the lives of individuals

equals

increased opportunities for community inclusion living and working when transitioning to adulthood



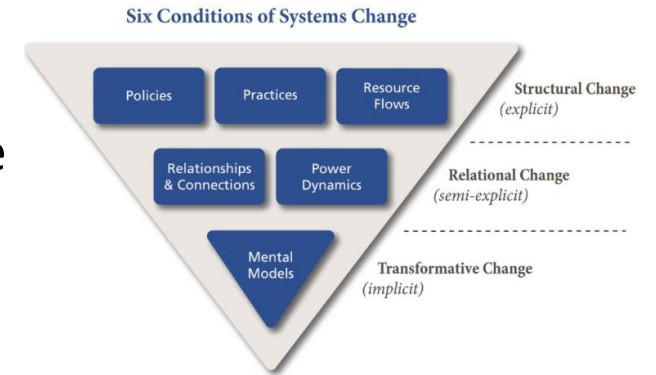
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# Setting the Foundation for Community Inclusion: Role of Schools

- Primary and secondary schools provide a ready vehicle to educate and drive attitudes around community inclusion for individuals with I/DD and their families, and our broader communities at large.
- Ideally, what could be role of our school systems in helping to build more positive attitudes and educate around community inclusion in primary and secondary schools?
  - How can we do this without adding an extra load on an already stressed system?
  - How can we be the change you want to see?



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## **“Good Life”**

**We start planning and exploring for our children's “Good Life” as soon as they are born. Navigating the new world we face as we get an diagnoses can be overwhelming. Easy to lose sight of plans for our child’s “good life” or even to forget to still dream for their future.**

The Charting the **LifeCourse framework** was created to help individuals and families of **all abilities and all ages** develop a **vision for a good life**, think about what they **need to know and do**, **identify how to find or develop supports**, and **discover what it takes to live the lives they want to live**. The framework is the keystone for supporting a community of learning that champions transformational change through knowledge exchange, capacity building, and collaborative engagement.

[LifeCourse Framework website](#)

[Person Centered Tools](#)

**Core Belief: *All people have the right to live, love, work, play and pursue their own life aspirations.***

**How can we use this to help within an Individualized Education Program(IEP)**

[Framework Infographic](#)

Parental concerns, if any, about their child's academic and functional performance in school:

[Framework Principles](#)

Parent /student's vision for the future: (Include, specifically, vision for after high school, if appropriate.)

## **How can we use this to help within an Individualized Education Program(IEP)**

Parental concerns, if any, about their child's academic and functional performance in school:

Parent /student's vision for the future: (Include, specifically, vision for after high school, if appropriate.)

Take time to think about these questions before the IEP meetings, think about what is needed for the next year to achieve goals for your child's future. This is at all ages all transitions not just at 14 when you have to start talking about transitioning to adulthood. Pre-k to K, K-1, 1-5 grade, middle school, high school all these are transitions that lead to adulthood.

# Questions for



- If you knew then what you know now, what would you do differently to prepare yourself or your loved one for transitioning to community-based, integrated living and working?
- What are the key transitions K-12 ? Were you (or your child) asked about where they (you) wanted to live or work?
- What does it mean to have an I/DD-informed school?
- As parents and individuals, how could we work together to make our schools more I/DD informed?

*Key to System Change:*

# **Creating I/DD Informed Communities**

- **What does it mean to be I/DD informed? Must apply to schools, policymakers, your neighbors, service providers**
- Question for all – write in chat
- What is our ACT for today? How can we be the change we want to see? Think about what can I do to be the change I want to see?

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## Our Thanks to All

- Join our Mailing list
- Visit our Web site
- Read our monthly newsletter
- Follow us on Social Media
- Come back next month: “I/DD Policy Think Tank Follow up”

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