

# Quality of Life and Emotional Health of the Family: A panel discussion

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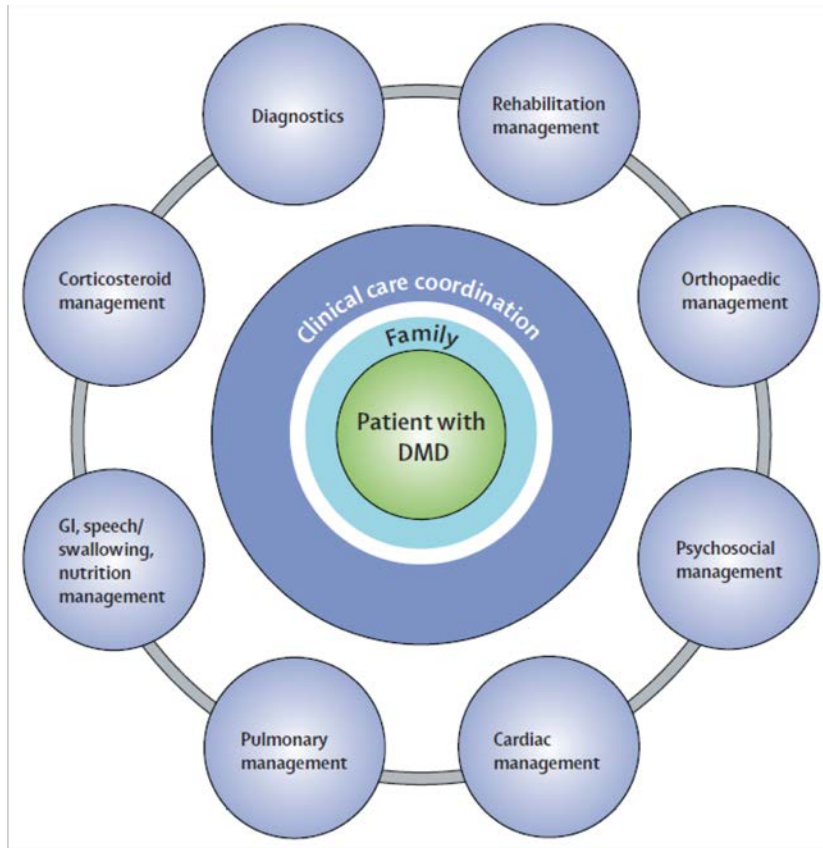
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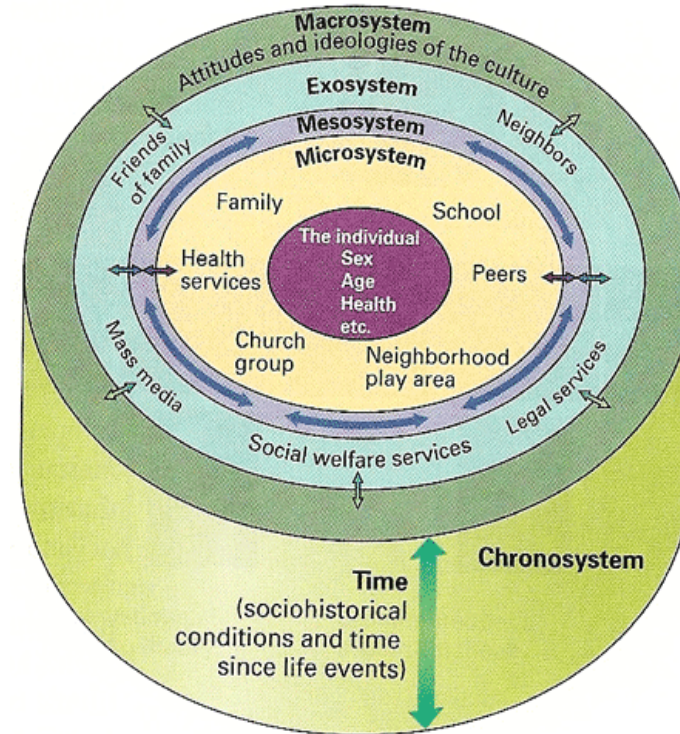
# Panel Introductions

# Similar Approaches – DMD Care Recommendations and “Bioecological” Models of Family Development

DMD Care Considerations



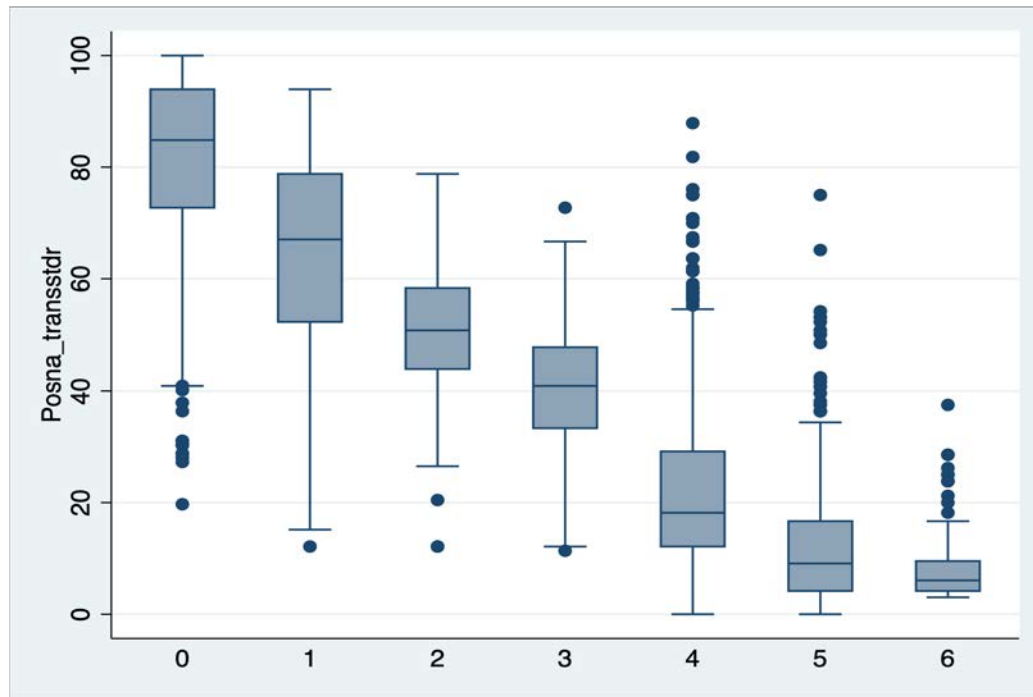
Bronfenbrenner 1979



# What is Quality of Life?

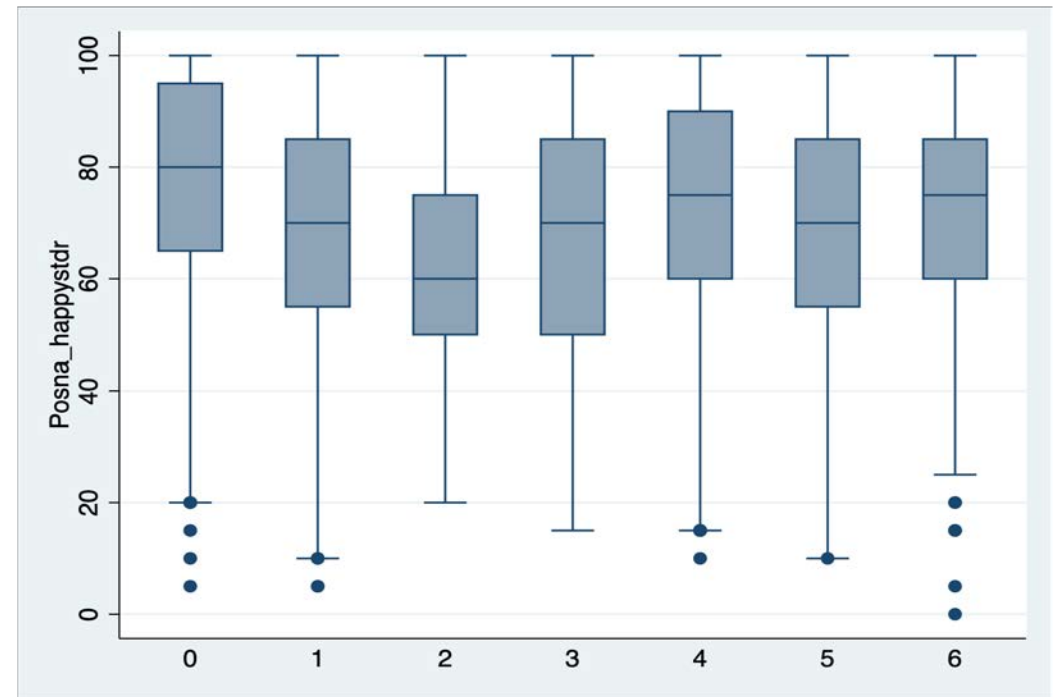
As clinicians we might sometimes forget that we call many questionnaires “Quality of Life” forms. BUT, what many of those tools often ask about is MOBILITY or what we call FUNCTIONAL HEALTH. And, many research studies tend to focus mainly on the person with DMD.

## Mobility



Vs.

## Happiness



Most people though are likely to say that “Quality of Life” is more related to *happiness* or *life satisfaction*. That’s a complex concept, and doesn’t happen in a one-person bubble.

So maybe **MOBILITY** ≠ **Quality of Life**, at least not directly.

*What impacts quality of life then?*

Maybe instead it's something like this:

**Strength -> Mobility -> Participation -> Quality of Life**

But there are other parts to this. What affects an individual's *participation*?

- Strength?
- Fatigue?
- Mobility?
- Health?
- *Behavior?*



# Impact of Behavior on Individual Quality of Life?

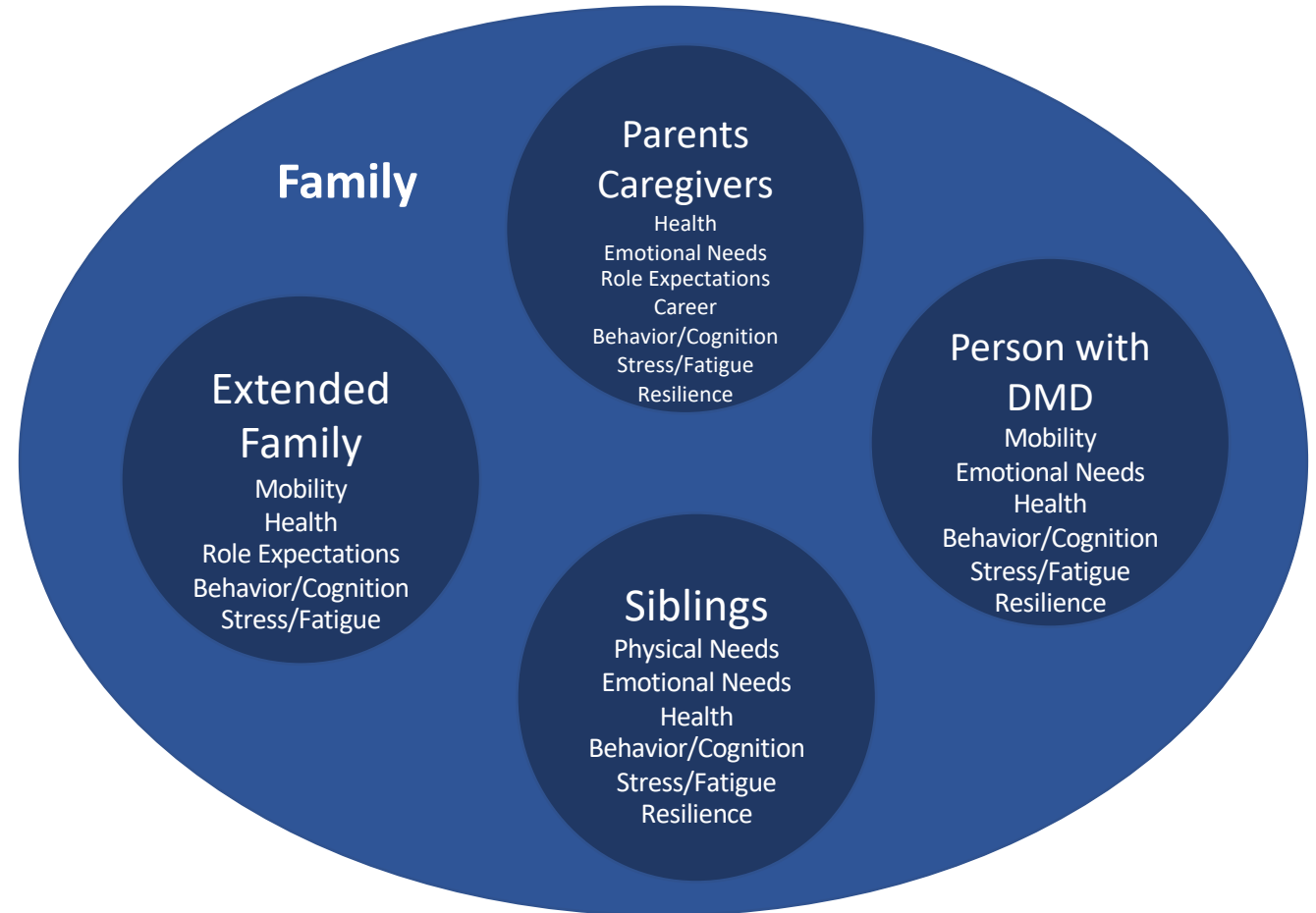
- There's dystrophin in the brain, too.
- DMD not only affects strength and mobility, but *may* also affect *cognition and behavior*. This varies. Many describe “autism-like” features:
  - Socioemotional delay – not “acting their age”
  - Emotional outbursts
  - Anxiety
  - Behavioral rigidity
  - Challenges with attention
  - Compulsive or repetitive behaviors
  - Social disinterest / withdrawal
- *May* create challenges in social/peer group *participation*
- *May* lead to a frustrating mismatch between expectations and reality (at least for parents and family) that can also impact *participation*
- So at least in part, a *combination* of *mobility-related* and *socioemotional* challenges for people with DMD can impact QoL of the family.



# Impact on Family Quality of Life: Challenges

- **Caregivers**

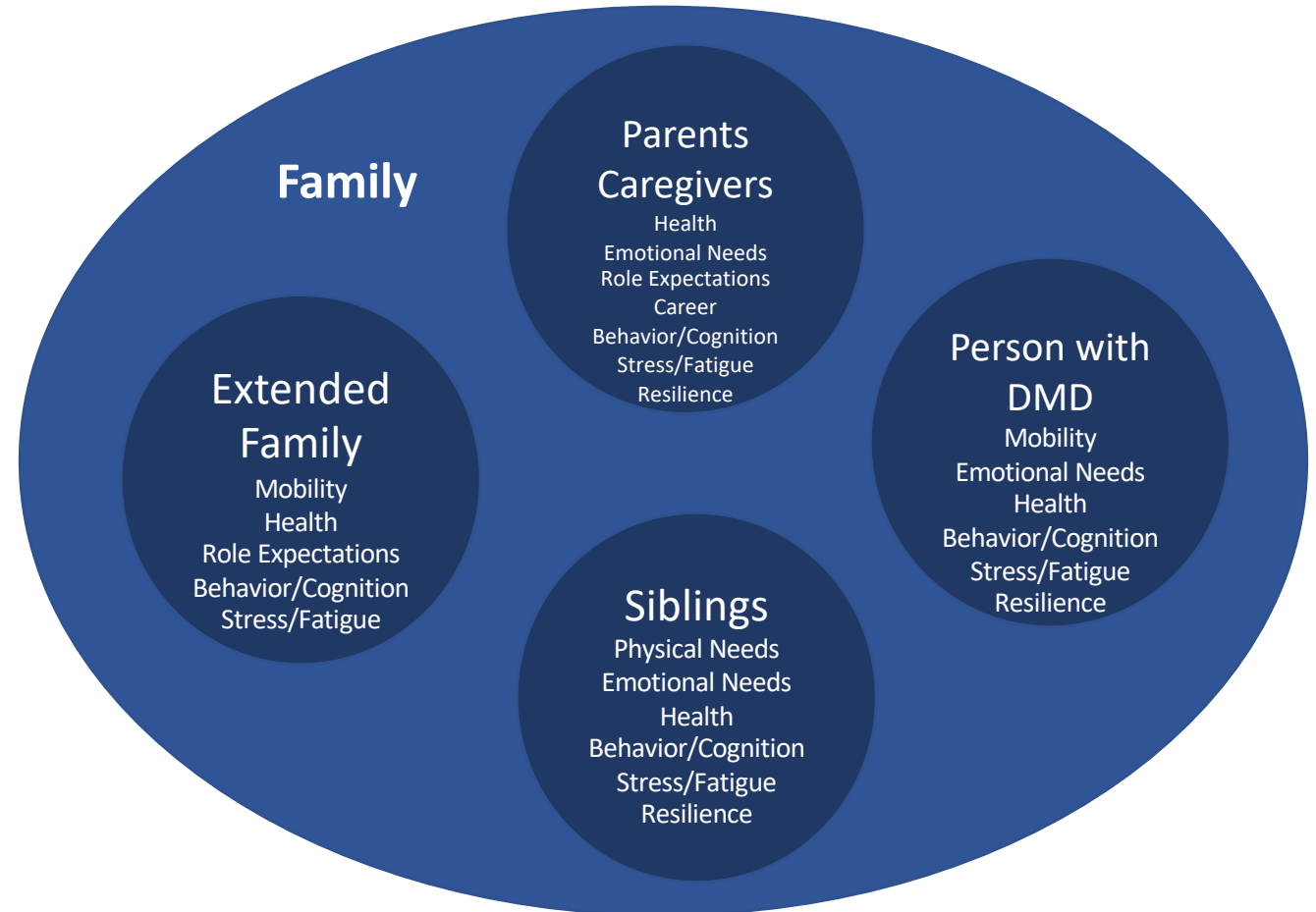
- Physical stress, fatigue and health
- Emotional stress
- Grief / chronic sorrow
- Worry about the future
- Financial stress / Job stress
- Not enough time to get everything done
- Dealing with regular disruption (illnesses, clinic visits, school meetings, etc.)
- Role expectations - Balancing relationships with other family members (spouse, children, parents, etc.)



# Impact on Family Quality of Life: Challenges

- **Siblings**

- May have less time with parents / caregivers on their own individual activities
- Role expectations - May have their own caregiving responsibilities or earlier adult-like roles
- Worry / Stress / Grief
- Independence and autonomy – can be more OR less?

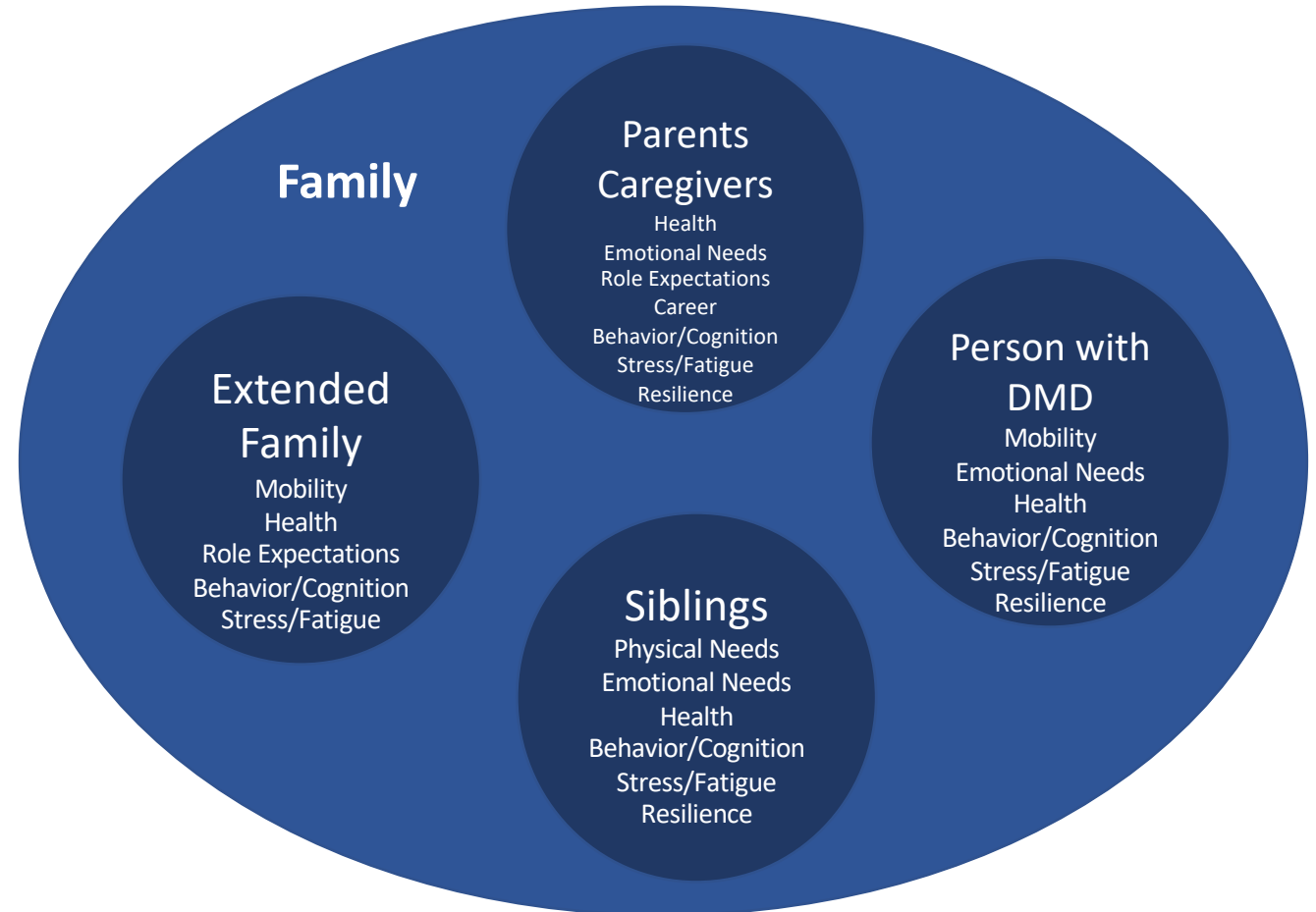




# Impact on Family Quality of Life: Challenges

- **Extended Family**

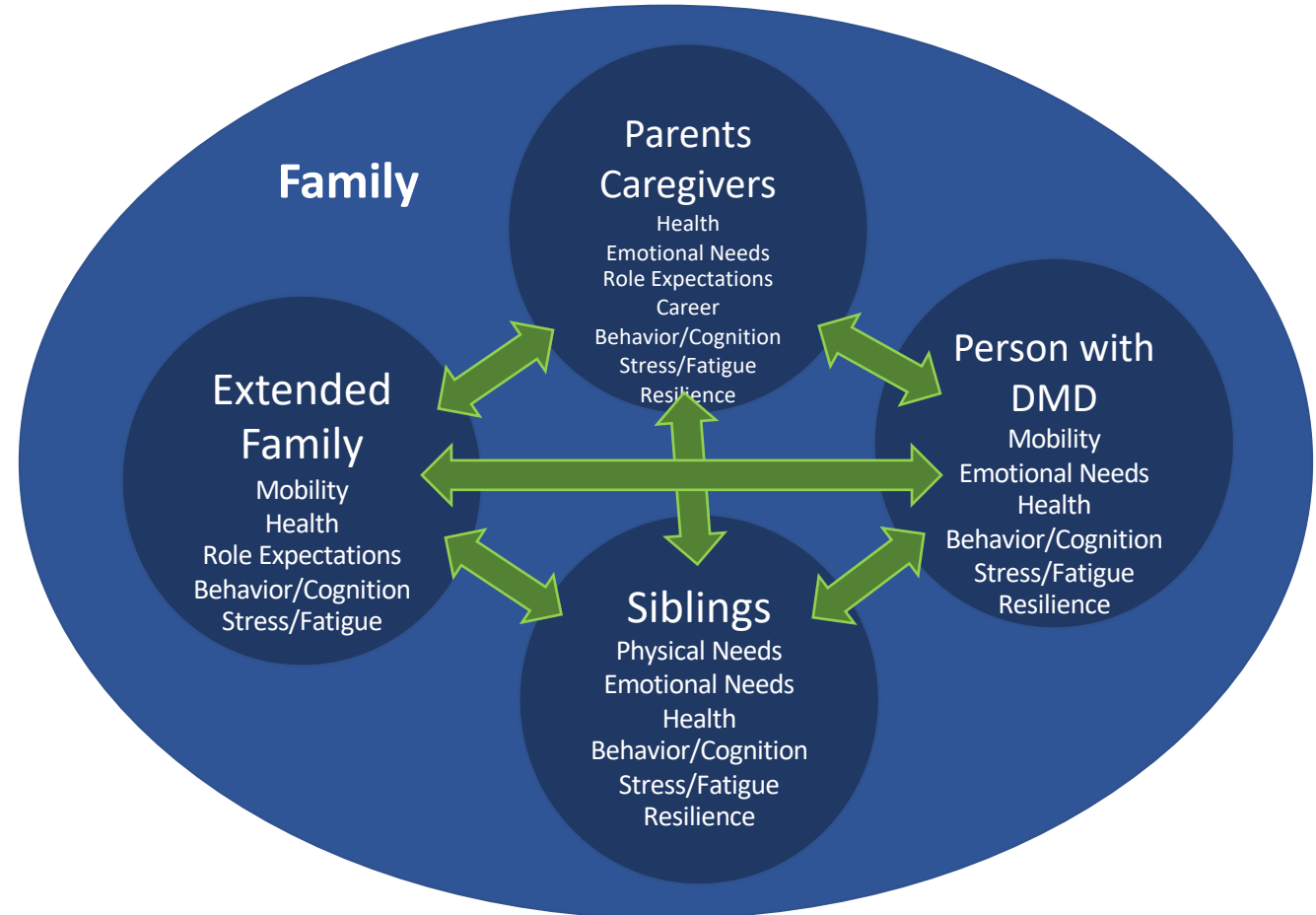
- May have their own care needs / expectations
- May not understand DMD or the challenges it brings
- May not know they can play a key supporting role



# Impact on Family Quality of Life: Positive Factors from Mutual Supportive Relationships

Families can be incredible and supportive teams! Some see opportunities to:

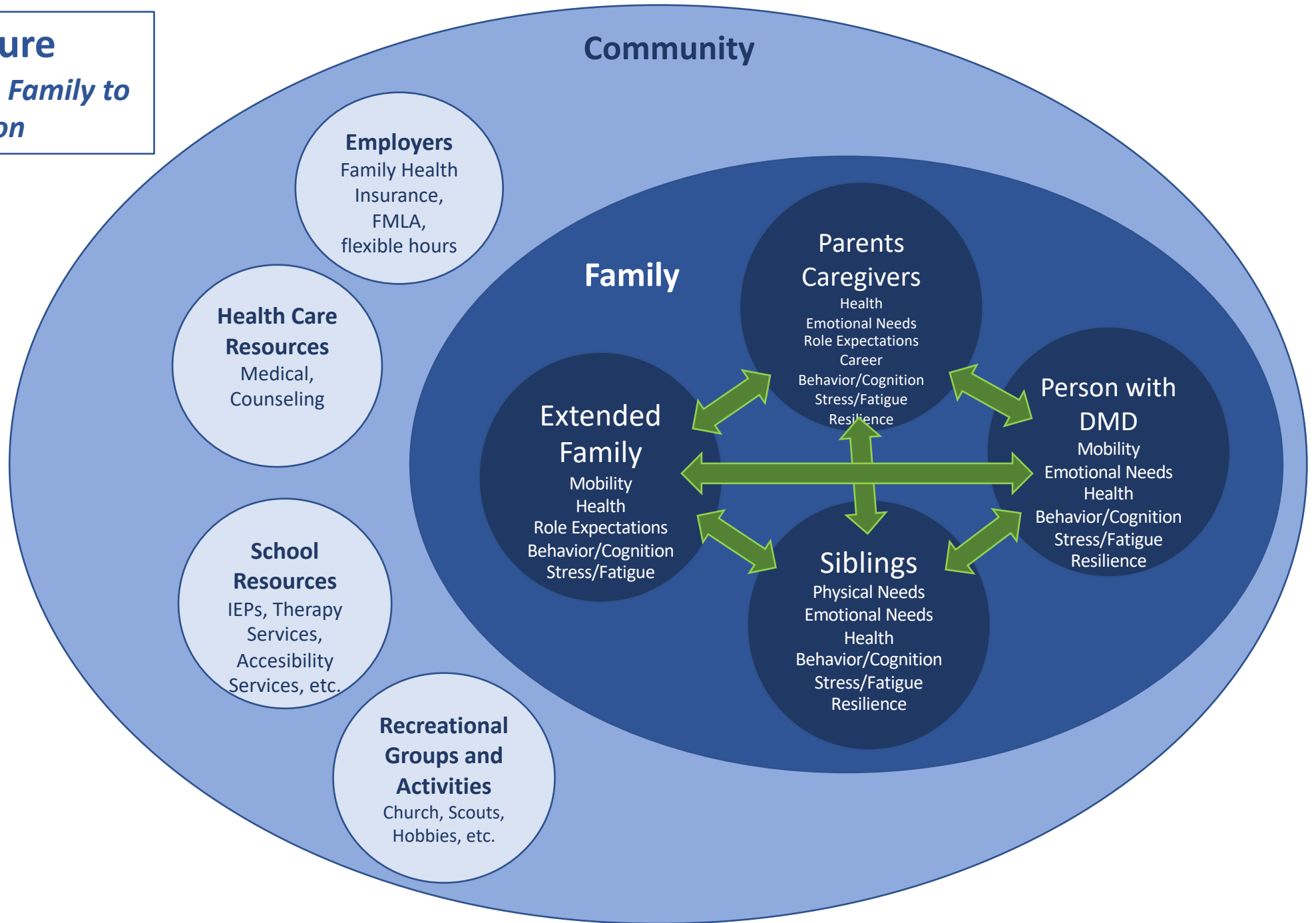
- Share and discuss feelings / worries / anxiety
- Focus on health and wellness of the whole family
- Build resilience, autonomy and self-confidence
- Develop closer and more meaningful relationships
- Share responsibilities for care, but also share resources
- Focus on what is personally most important in life
- Advocate for each other
- Share in search for resources



# The Bigger Picture

*Looking Outside the Family to Enhance Participation*

## State / National



## The Bigger Picture

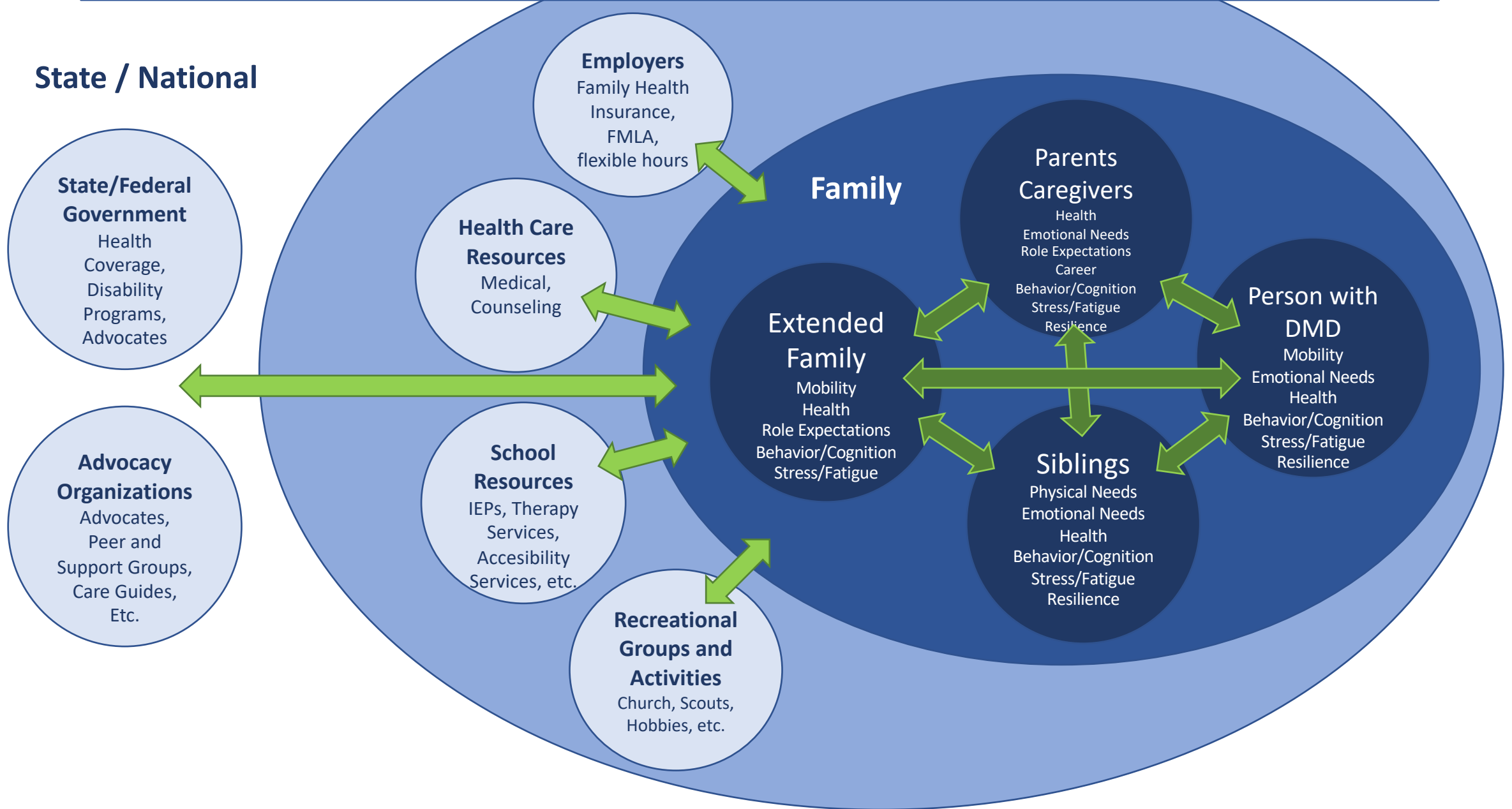
Looking Outside the Family to  
Enhance Participation

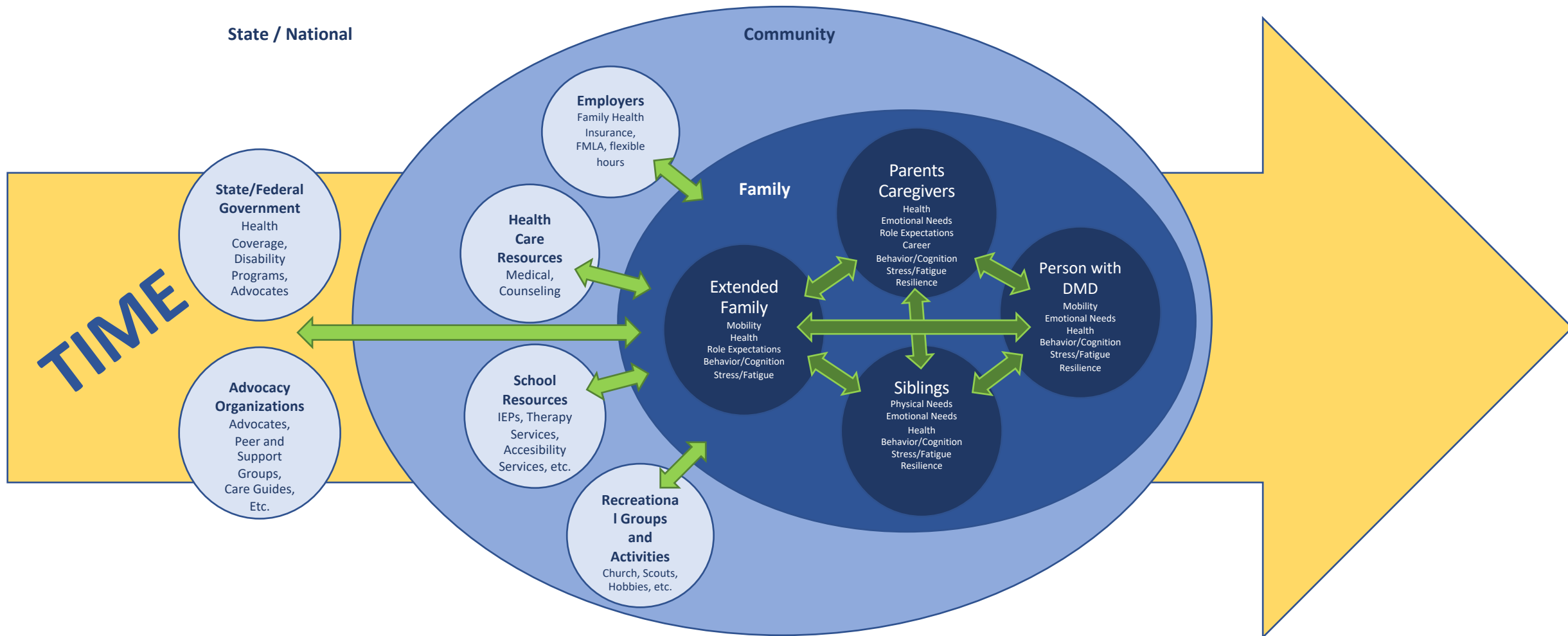
# Enhancing Participation

- It's hard to ask for help and resources, or to even know what to ask for!
- Finding and getting those resources can sometimes be frustrating and time consuming. Team approaches can work best.
- Resources can be at the community, state or national level.
- Resources should support not just the person with DMD, but the *entire family*:
  - Medical care and insurance
  - Health and wellness (*physical AND socioemotional*)
  - Behavioral health
  - Educational support
  - Assistance from employers
  - Leisure activities
  - Peer support

# Support “web” can enhance participation and facilitate positive Quality of Life

## State / National





**Needs, resources and relationships also change over time. There's a need for periodic "readjustment" to maximize participation and QoL. Some parts can vary in importance at different ages / life stages.**

# Discussion