

Evaluation of the FACT Developmental Disability Family Support Program

Submitted by:



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Agenda

- *Personal Capacity for Achieving a Good Life Scale*
- Focus Groups
- *Life Outcomes Progression Scale*

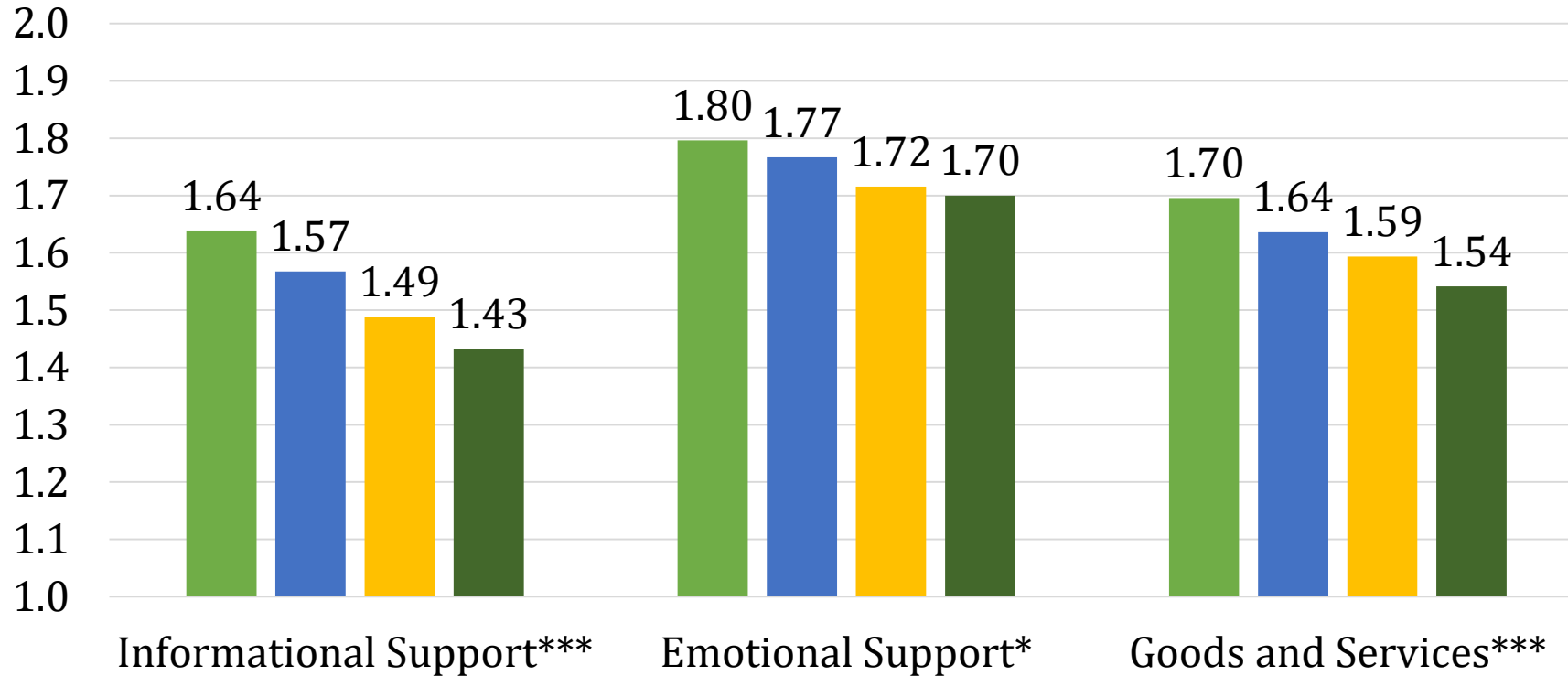
Personal Capacity for Achieving a Good Life Scale

Domains:

Informational Support (4), Emotional Support (3), and Goods and Services (7)

Domains

Average urgency of needs scores overtime by domain ($n = 85$)



Scoring

1: Empowered / Thriving

2: Building Capacity

3: Urgent Need

*** $p < .001$; * $p < .05$

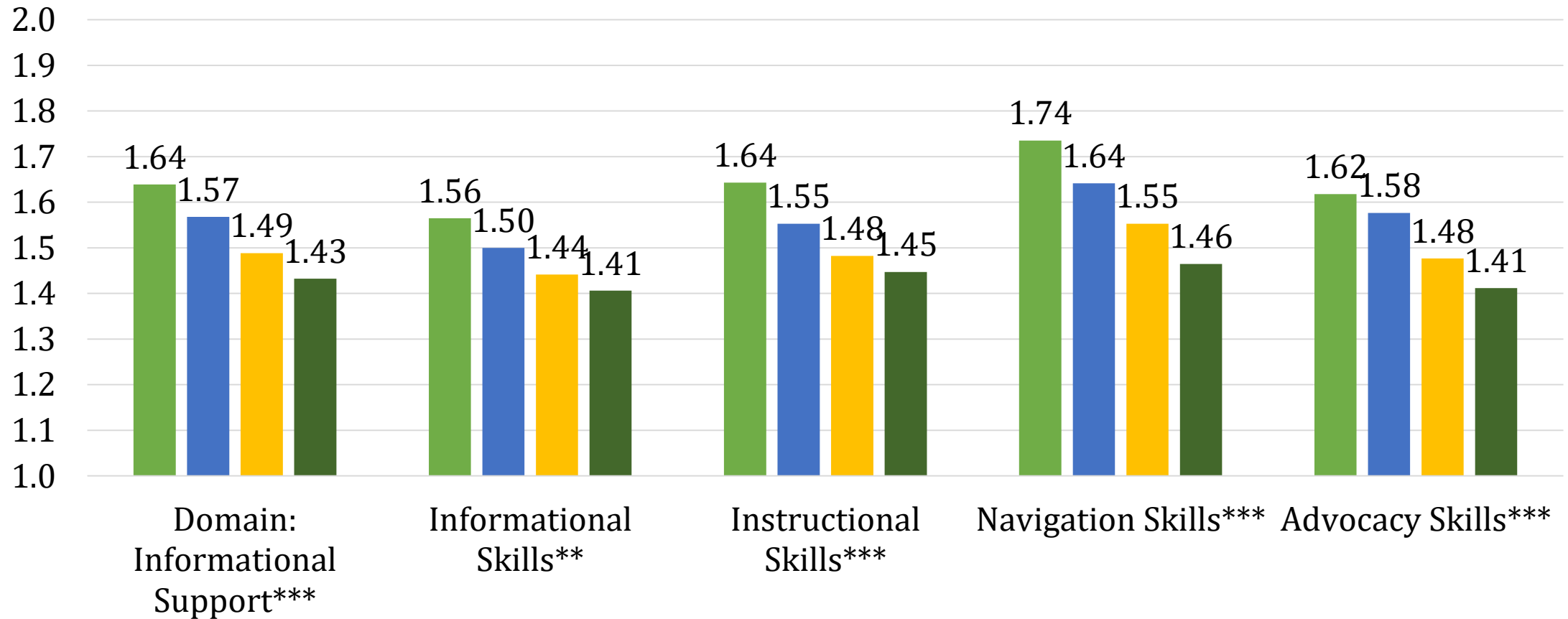
■ Time 1

■ Time 2

■ Time 3

■ Time 4

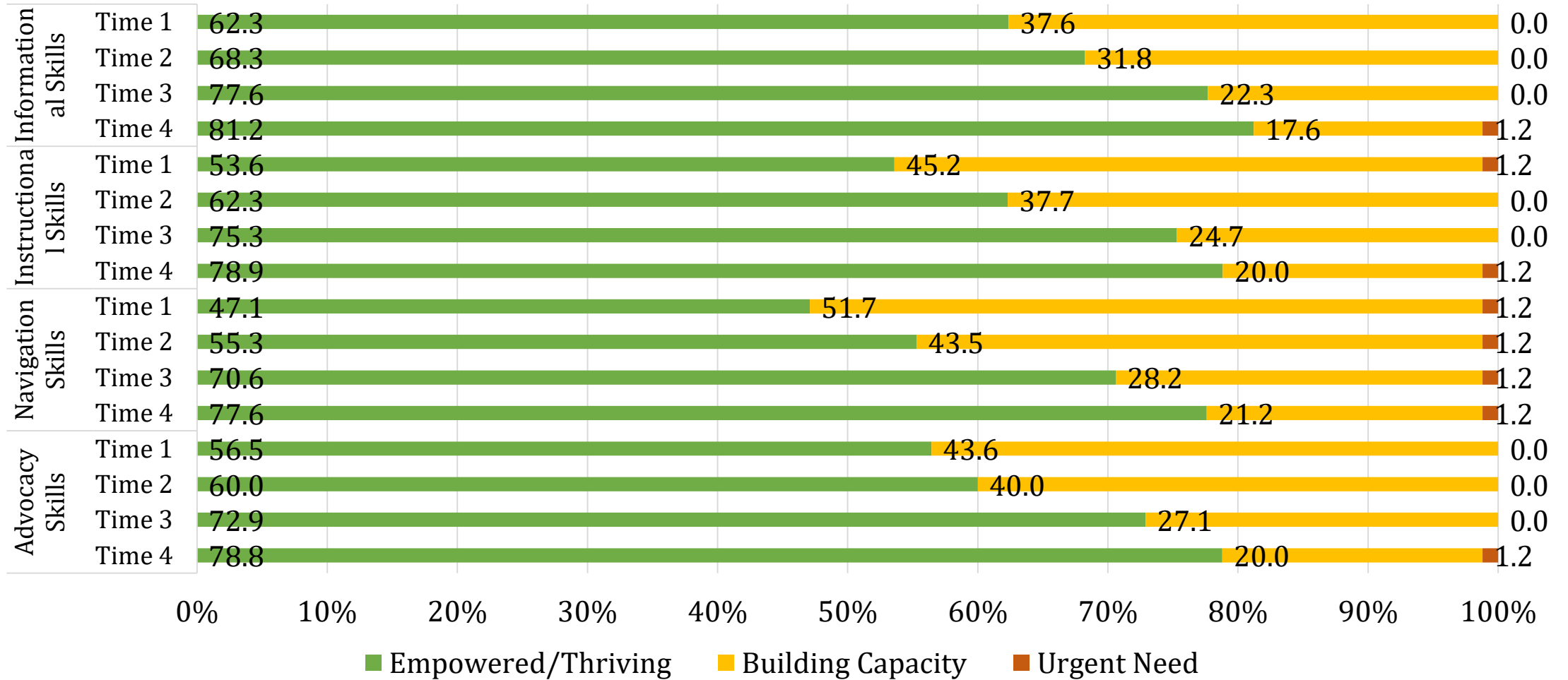
Informational Support: Average Scores



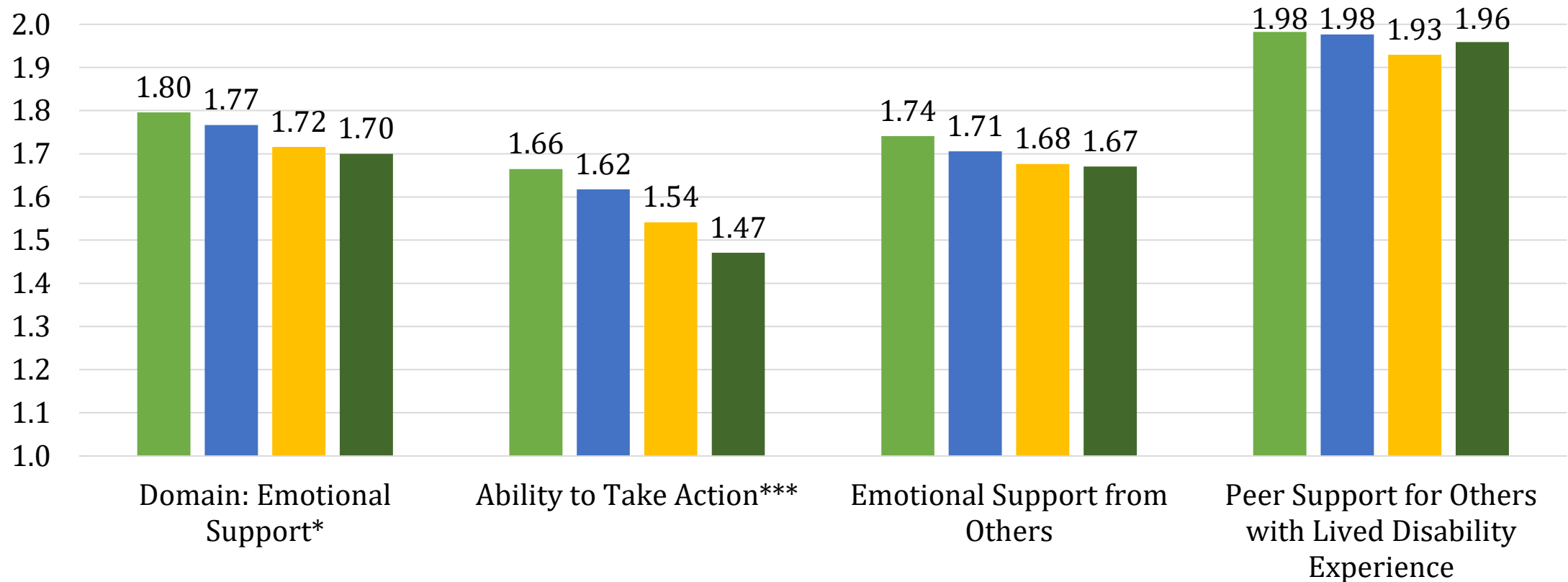
*** $p < .001$; ** $p < .01$

■ Time 1 ■ Time 2 ■ Time 3 ■ Time 4

Informational Support: Percent Scores



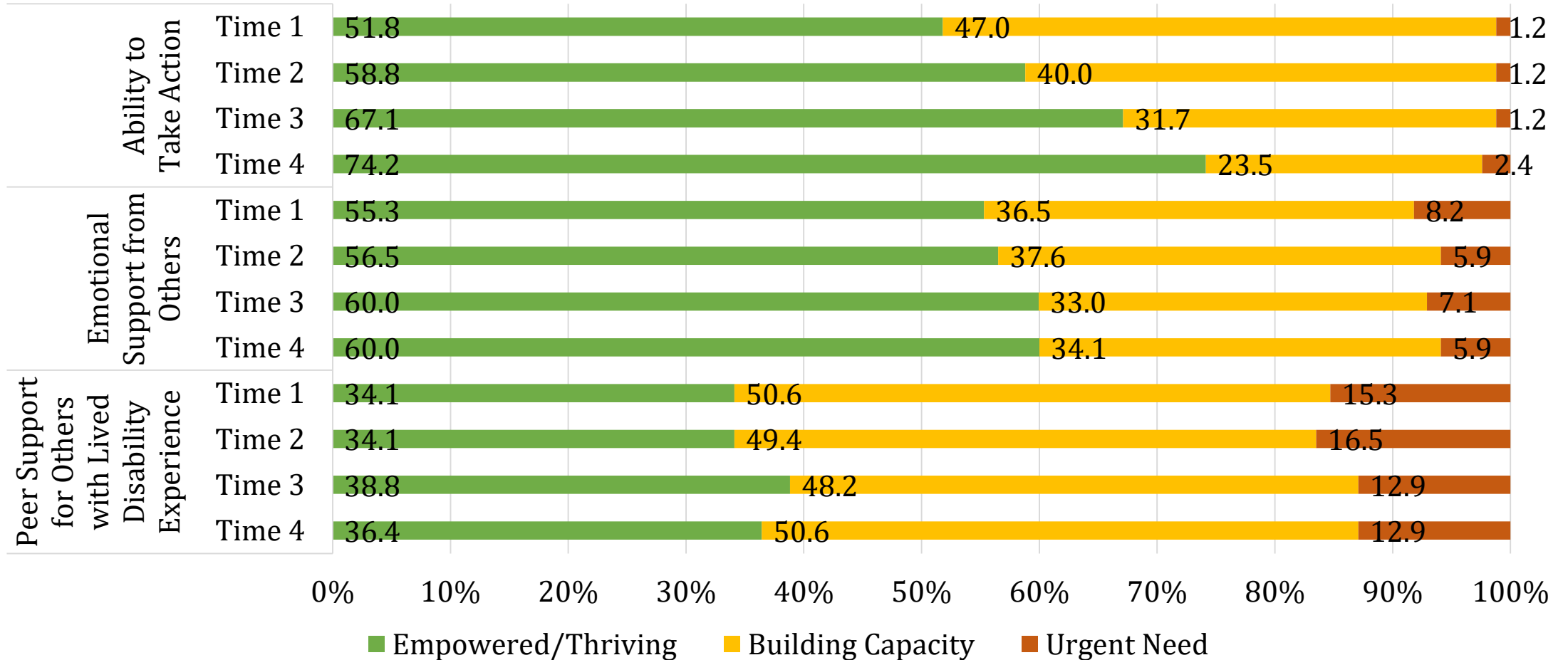
Emotional Support: Average Scores



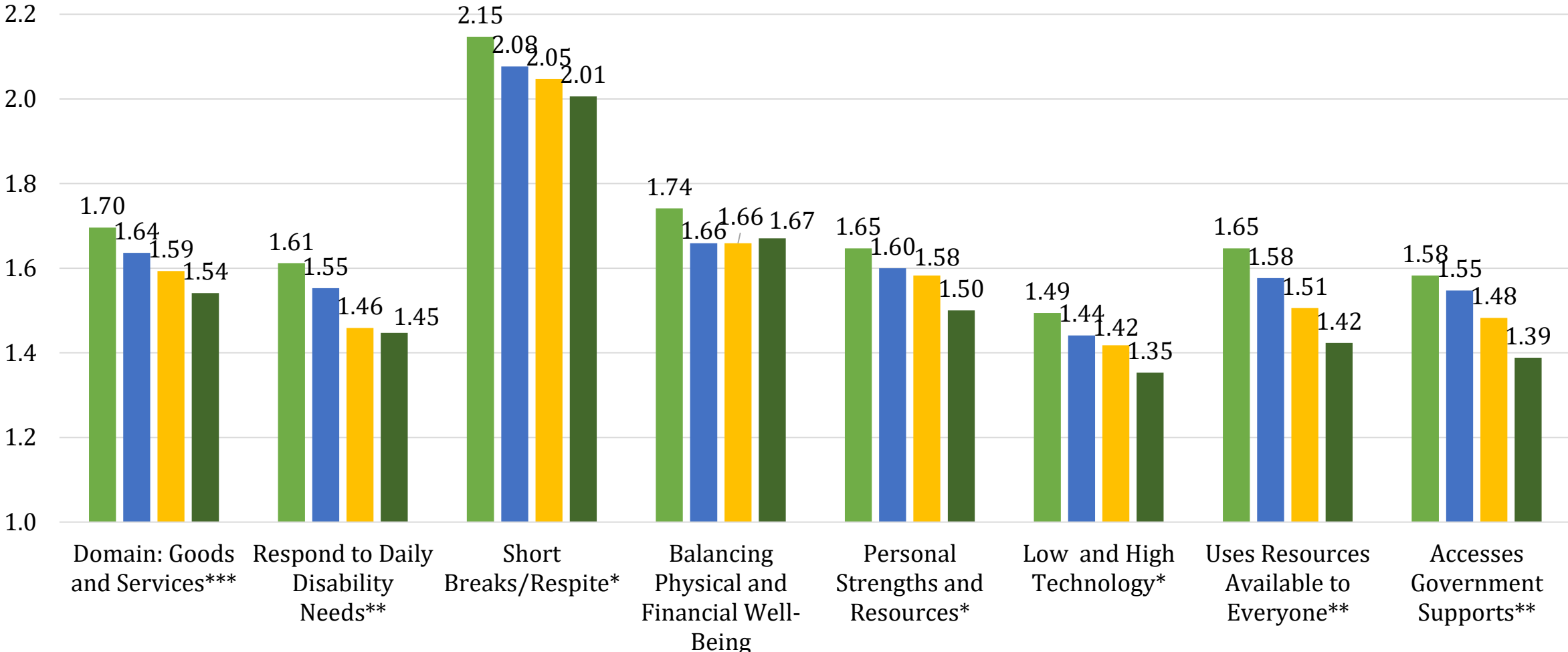
*** $p < .001$; * $p < .05$

■ Time 1 ■ Time 2 ■ Time 3 ■ Time 4

Emotional Support: Percent Scores



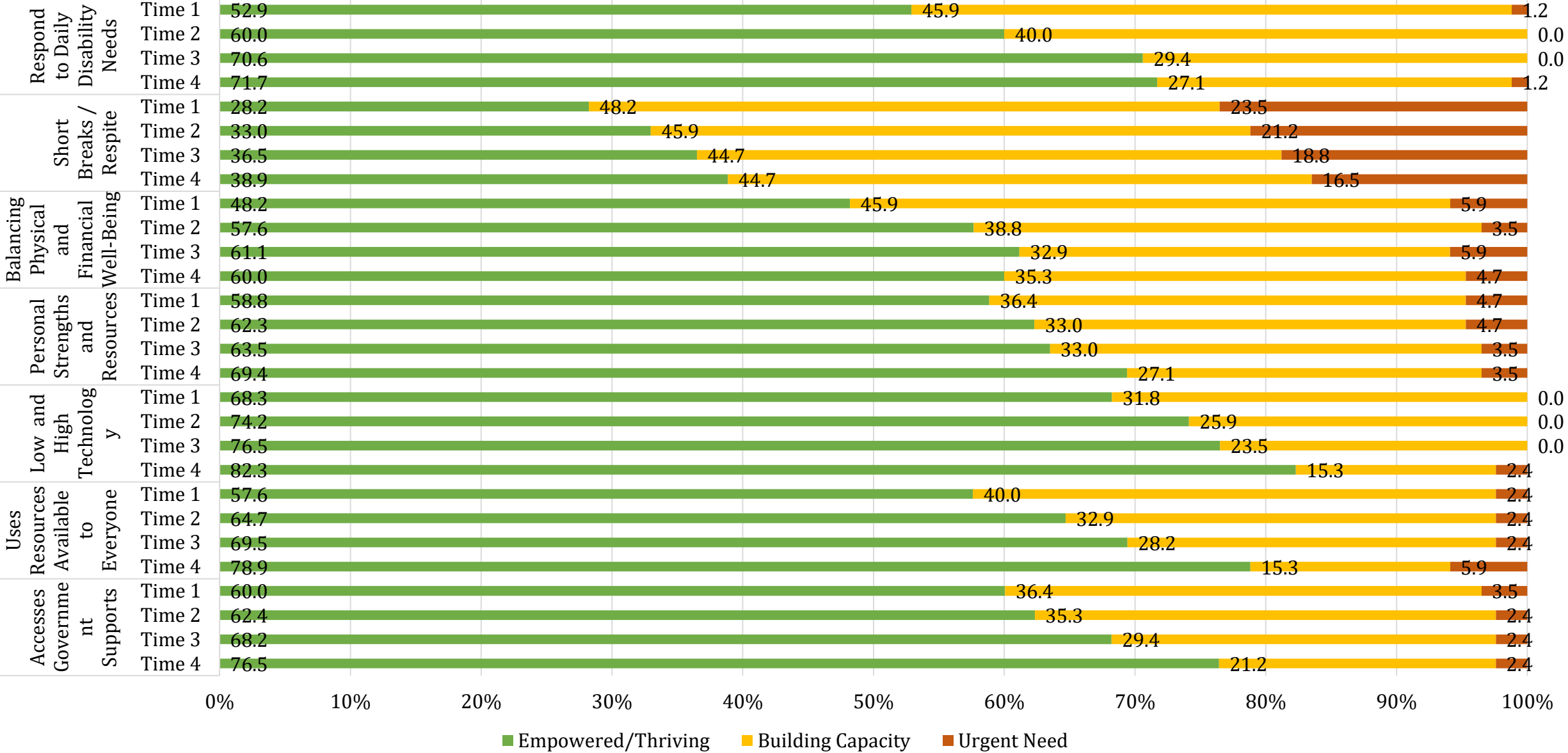
Goods and Services: Average Scores



*** $p < .001$; ** $p < .01$; * $p < .05$

■ Time 1 ■ Time 2 ■ Time 3 ■ Time 4

Goods and Services: Percent Scores



Personal Capacity for Achieving a Good Life Scale: Key Findings

- Participation in the *DD Family Support Program*:
 - **Significantly increases** families' **personal capacity** to achieve a good life across all 3 domains:
 - *Informational Support****
 - *Goods and Services****
 - *Emotional Support**
 - **Significantly decreased** avg. urgency of needs ratings for 11 of 14 items
- Areas of greatest improvement from Time 1 to Time 4:
 - *Navigation Skills* (Domain: *Informational Support*)
 - *Uses Resources Available to Everyone* (Domain: *Goods and Services*)
 - *Advocacy Skills* (Domain: *Informational Support*)

Personal Capacity for Achieving a Good Life Scale: Key Findings (cont.)

- Resources or information identified as most needed at Time 1:
 - *Short Breaks/Respite* ($M = 2.15$)
 - *Peer Support for Others with Lived Disability Experience* ($M = 1.98$)
 - *Navigation Skills; Emotional Support from Others; Balancing Physical and Financial Well-being* ($M = 1.74$)
- Resources or information identified as most needed at Time 4 :
 - *Short Breaks/Respite* ($M = 2.01$)
 - *Peer Support for Others with Lived Disability Experience* ($M = 1.96$)
 - *Emotional Support from Others; Balancing Physical and Financial Well-being* ($M = 1.67$)
- Areas of least improvement from Time 1 to Time 4:
 - *Peer Support for Others with Lived Disability Experience* (Domain: *ES*)
 - *Balancing Physical and Financial Well-Being* (Domain: *G&S*); *Emotional Support from Others* (Domain: *ES*)
 - *Short Breaks/Respite* (Domain: *ES*); *Low and High Technology* (Domain: *ES*)

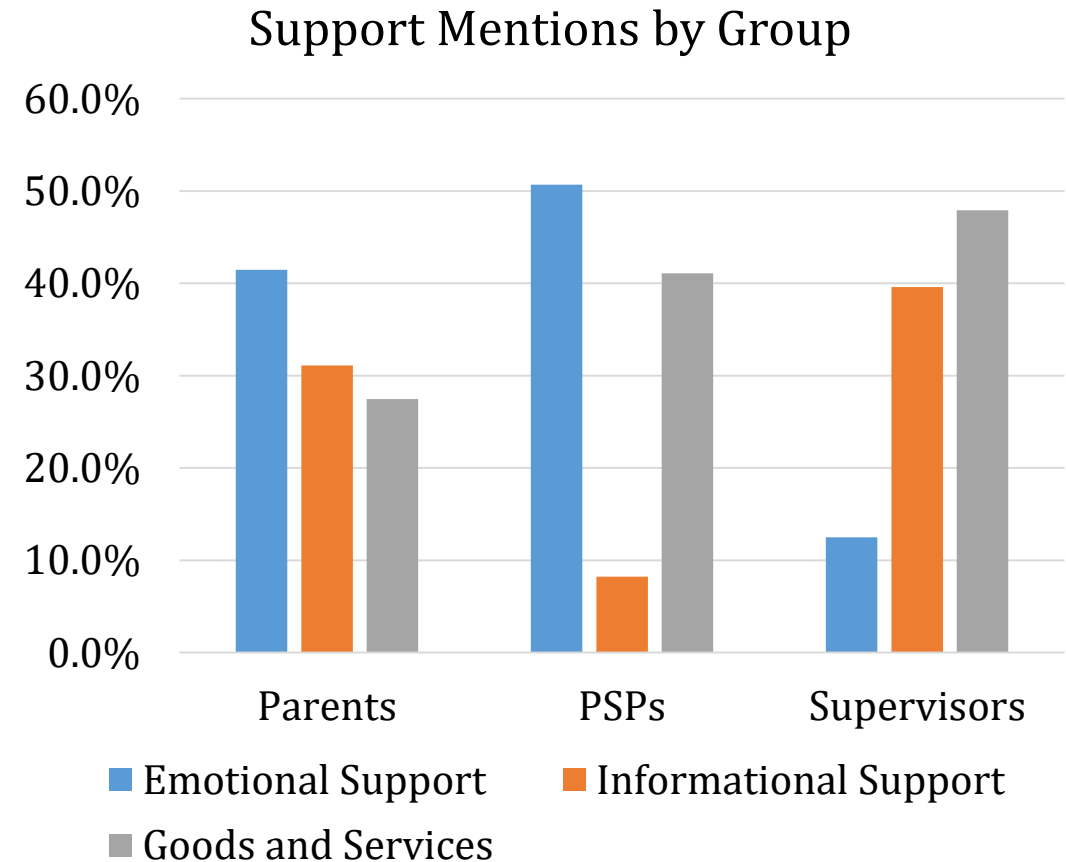
Focus Groups

Participants: Parents, PSPs, and Supervisors

Focus Groups

- 10 Parents (4 focus groups)
- 8 PSPs
- 3 Supervisors

- Transcribed audio recordings
- To compare focus group and survey results, coded quotes by *3 Personal Capacity for Achieving a Good Life Scale* domains



Emotional Support

- Most common initial and continuing support
- Crucial role of PSP as source of social and emotional support
 - Parent 1: *I consider my worker a friend. Like she's the only one that I have. I don't have any friends online. I don't have any friends in-person.*
 - Parent 2: *It's very isolating. That's giving you the hand you need to hold... I always tell her, I give her hug and tell her, "I couldn't do this without you." I don't know how I did it without you.*
- Parents with more robust social support systems reported that they were not interested in expanding emotional support from others, in general (e.g. family, community)

Emotional Support (cont.)

- Greater openness to, but also a reduced need for, other close relationships
 - Parent: *My husband and I both have a huge family. We're both very family oriented. We spend a lot of time with family. I have a couple really close friends. But I think [PSPs] help us be more confident and more open for friendship... I don't think they've necessarily said, "You should go to this focus group and you'll meet your best friend for the next fifty years." But I think they keep you open. She makes you confident that you're doing a good job. I don't think personally, it's helping me find more friends. I don't know that I could handle any.*
- Support from their PSP bolstered their ability to harness existing members of their support system to target specific needs

Emotional Support (cont.)

When asked if having a PSP enabled families to expand the group of people who are able to assist and support them personally,

- Parent 1: *I'm going to say no. But I need to preface that by saying that "no" is a good thing. Because I think prior to finding a family support person I would confide in friends, and I would confide in family and they just don't understand. And they don't get it. And they'll say things that aren't helpful...And it's like, "Oh, I shouldn't even open my mouth, I shouldn't say anything. I should just talk about the weather." Yeah, I mean, I don't think I got more support outside of here, necessarily. They definitely opened me up to resources. But I think I've learned that because I have support in very specific areas...that gives me an outlet so I don't feel like I have to go to family and friends, and have to go through all that pain and agony.*
- Parent 2: *...so that's something that, with the support that I get here, and I think this was what she was trying to say too, is that you just don't need that other stuff. This is my foundation, I'm fine and here's just other stuff.*

Emotional Support (cont.)

- *Emotional Support* emerged as the most pervasive theme throughout focus group sessions
 - Catalyst for increased well-being
 - Conduit for meeting additional support needs
- Themes
 1. *Fostering Caregiver Well-Being*
 2. *Building Personal Capacity*
 3. *Conduit to Accessing Informational Support and Goods and Services*
 4. *Reciprocal Role*

Fostering Caregiver Well-Being

- Addressing isolation
 - Parent: *It's nice to have someone to ask how you are doing. It's not totally child-driven either...We meet once a month outside of the house because I never get outside of the house. And she's like, "Well let's go to breakfast,"...So, it's nice to actually have a reason to get out of the house and be out there.*
- Promoting self-care
 - Parent: *She always asks, my biggest problem is I don't spend enough time for myself and she's like, "Well did you go out and do something? Did you have a date night?" Because this is stuff we talk about. So it's like, "It's time for you to spend some time just with your significant other. She'll go, "You look really run down. You need to take some 'you' time." And it was very hard at first but now it's gotten a little bit easier. She cares about my health she can tell on my face... if it's a bad day. She's like, "Uh-oh, what's wrong?"...So I think she helps, personally, just being there with my health. But she also asks if I need any services or if there's something I need to look into just for me; which is amazing because you don't realize what you go through as parent with children with special needs. It's overwhelming.*

Building Personal Capacity

- Having a PSP reduces stress and builds confidence to meet the daily needs of their families
 - Parent 1: *Because I can unload. And I get that one-on-one time. And especially if I'm confused and I don't know what to do, and she gives me ideas it helps me be more calm and more relaxed around my family. And the stresses are not as high.*
 - Parent 2: *Right. You get the confidence to deal with what you have at home instead of second-guessing yourself and feeling the guilt.*
- Positive impact on parenting: “better mom”
- Reduced need for PSP
 - Parent: *It's very helpful. It's great support. I don't know that I need her as much as I used to. But I can see where some parents would. Because you are sometimes isolated. You know, some people don't get it. I mean, I don't need people to get it, but it's nice to have someone.*
 - Interviewer: *Do you think you need her less because of the support she put in place? Or because of your situation changing?*
 - Parent: *Both. I think it's both. She's helped me get stronger. It's a good sounding board so you don't seem as crazy as you feel.*

Conduit to Accessing Informational Support and Goods and Services

- Role of *Emotional Support* in fostering the ability to utilize *Informational Support* and access *Goods and Services*
 - Parent: *Yeah, sometimes when I have felt overwhelmed by everything, all the calls I've had to make she's like, "Well, let's write a list and here, let's do number one." You know, like I'm a little kid at school, you know and she's like "Okay, make this call now." But sometimes, it's really hard to just make the phone call because you've already made five hundred, you know, that week or something. But she gives you the push and helps you get the services for your kids with the correct information.*

Reciprocal Role

- Friends who share what is going on in their lives and care for one another
 - Parent: *When she asked me to come to the group and I was like sure and I was like, “well what kind of questions are they going to ask?” And I was like, “how long have we been working together?” You’ve been helping me and, you know. And I say working together because I ask her about her boys, you know... I’m trying to be supportive for her too so I think I’m helping her a little bit, too. I can’t believe it’d been that long since we’ve been seeing each other.*
- Contributes to a sense of purpose and giving back

Key 'Ingredients'

Parents

- Flexible
- Personal
- Available
- Responsive
- Resourceful
- Experienced (knowledge + empathy)
- Caring

PSPs

- Trust
- Respect
- Hope

Parents: Additional Support Needs

- Respite
- Assistance with calls
- Opportunities to interact with other FACT families
- Support groups or events (online and in-person)
- Employment opportunities / a job-share program
- Access to a back-up PSP

➤ Parent: *Well, if there were more support groups for parents that'd be great. Seems like there's a thousand and one things for my kid, not necessarily so many for me. And I would say the relationships I've had with family members or dating or whatever have struggled because they either try too hard to understand or they don't try enough. And it's just hard to kind of find that balance. So, I would love to find more things in St. Charles County area, **things like this** to kind of expand, unwind, and be around other people that you can relate to—just be around other people that you can relate to is so helpful. They don't even have to open their mouths, necessarily.*

Staff: Information / Resources Needs

- Supporting a family with an adult child with a disability
- Supporting families who are ineligible for paid supports because they have “too much money”
- Updated first protocol paperwork: adult/own guardian and child
- More financial resources to support families (e.g. rent)
- An ‘in’ person at each local provider organization
- Information on SSI for children
- Continuing education/training opportunities for PSPs and supervisors
- Opportunity for “veteran” PSPs to shadow one another and new hires
- Ability to report abuse and neglect directly

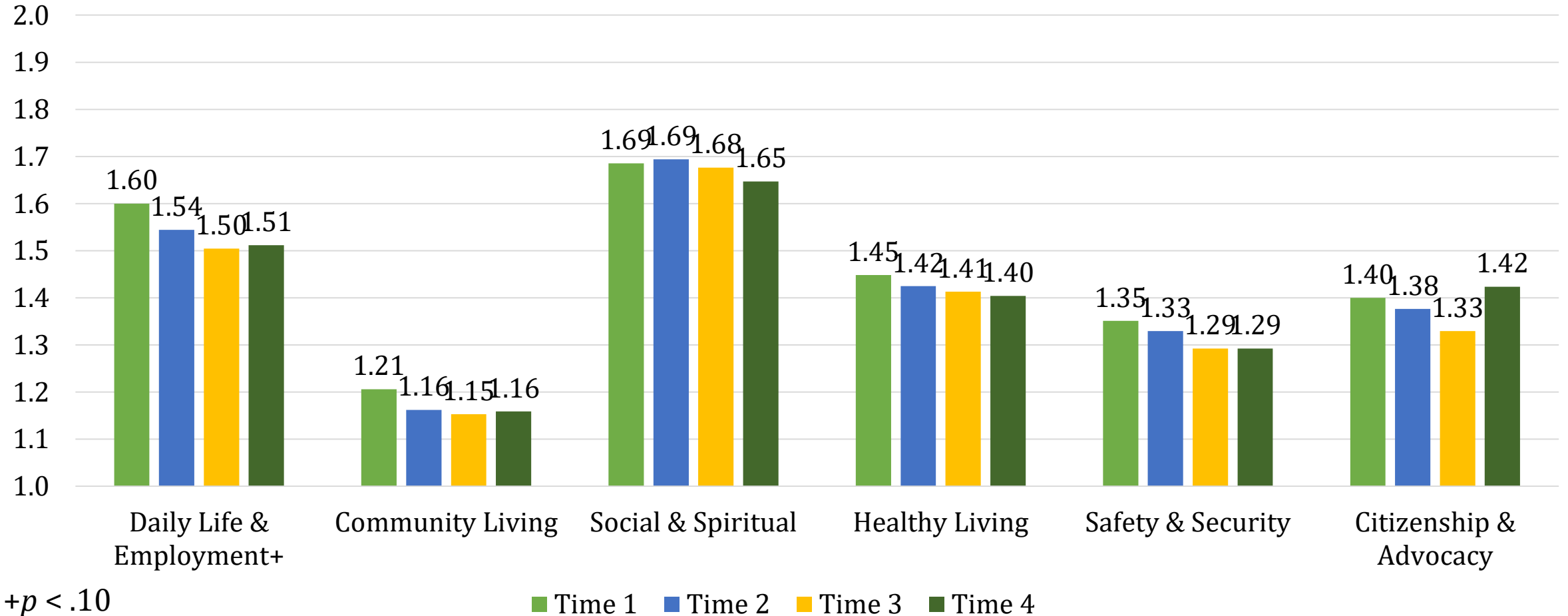
Life Outcomes Progression Scale

Domains:

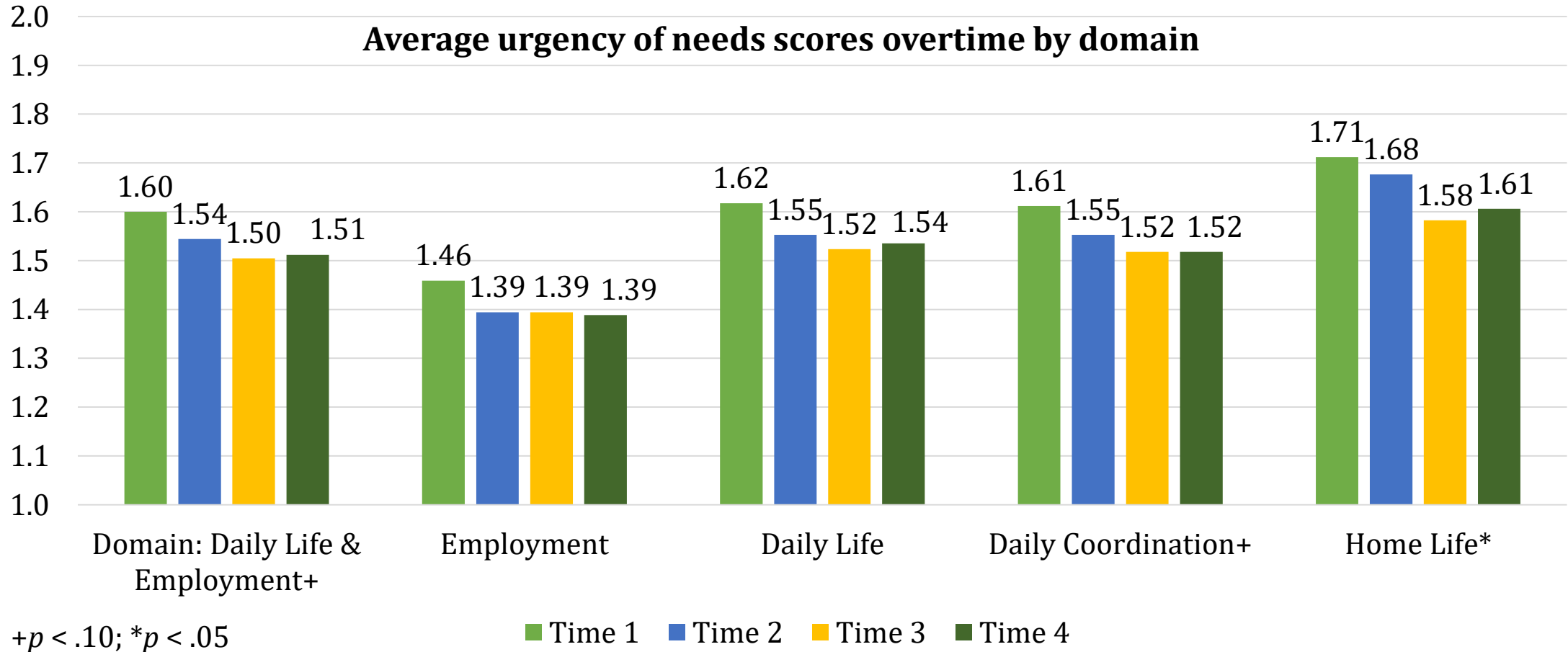
Daily Life and Employment (4), Community Living (2), Social and Spiritual (2),
Healthy Living (6), safety and Security (3), and Citizenship and Advocacy (1)

Domains

Average urgency of needs scores overtime by domain



Daily Life and Employment

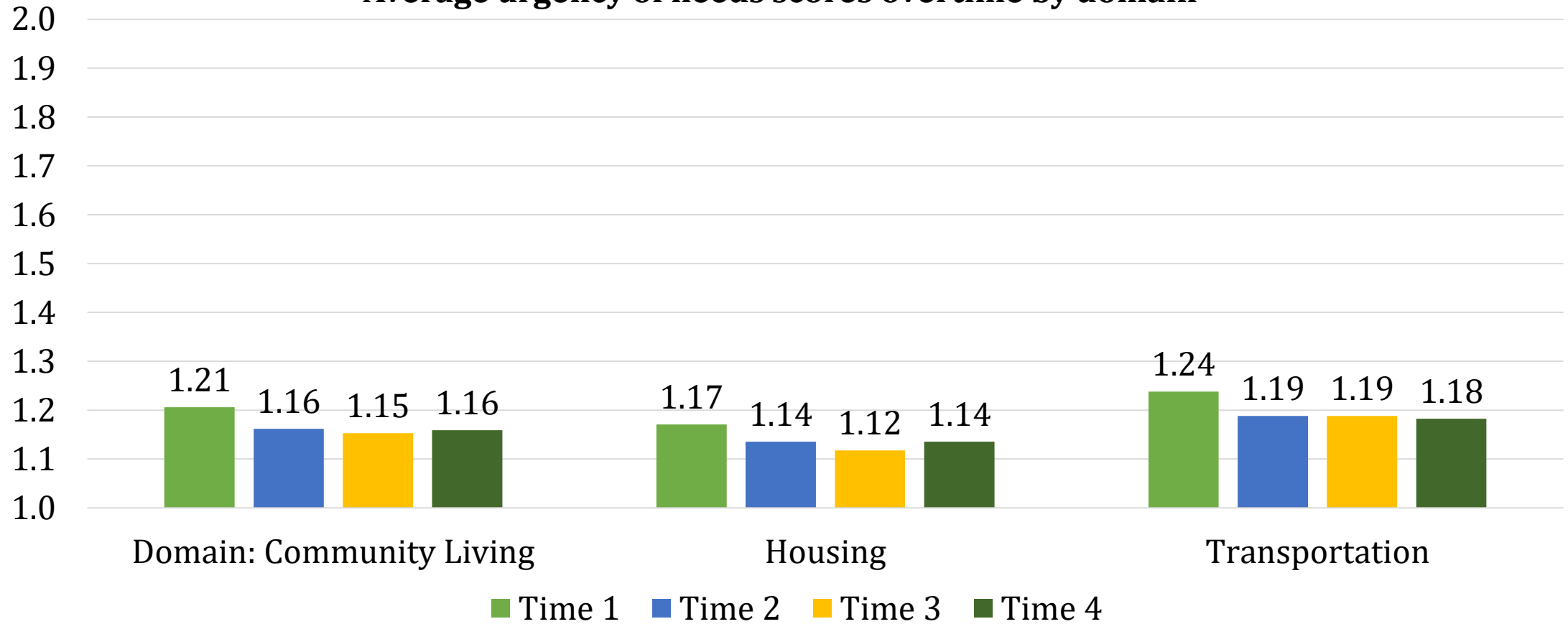


Daily Coordination: Parent meets activities of daily living needs and household functions for self and for family members (personal care and household tasks)

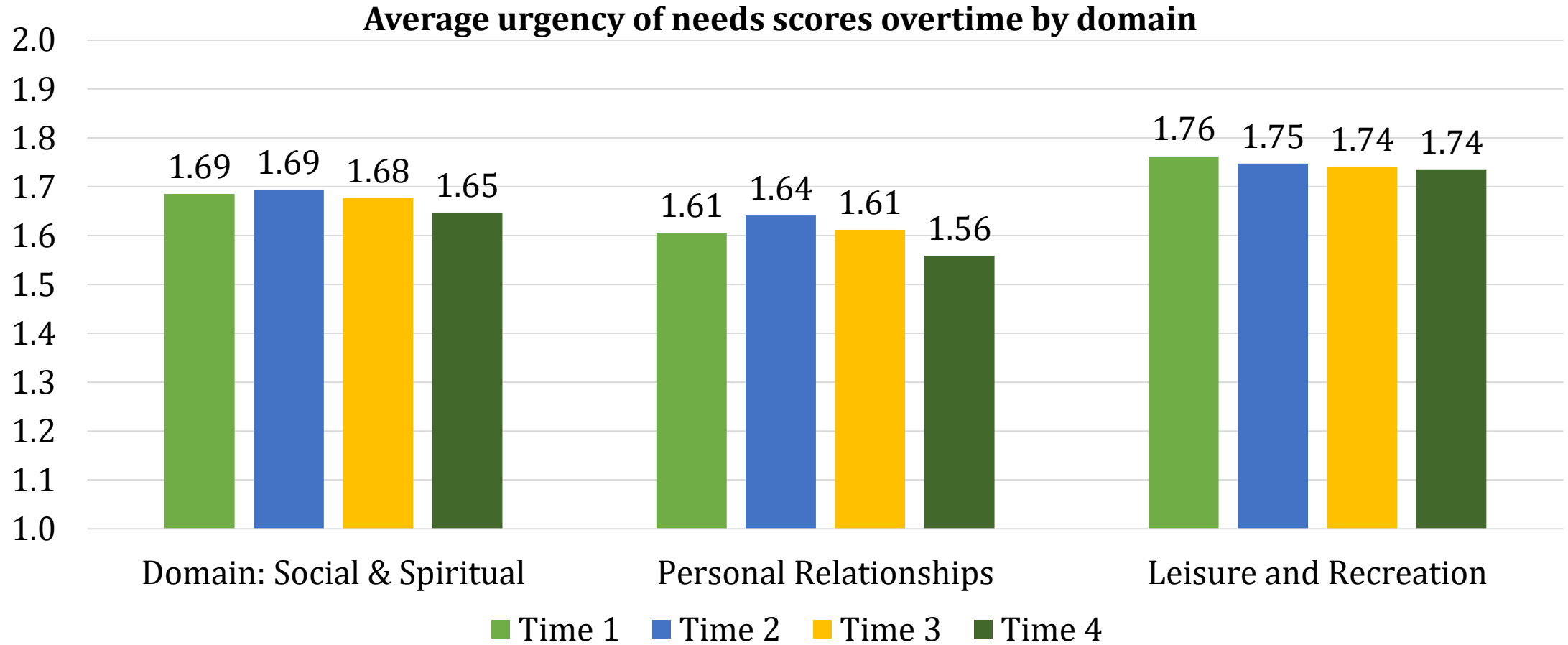
Home Life: Family home life is calm and family members get along with one another

Community Living

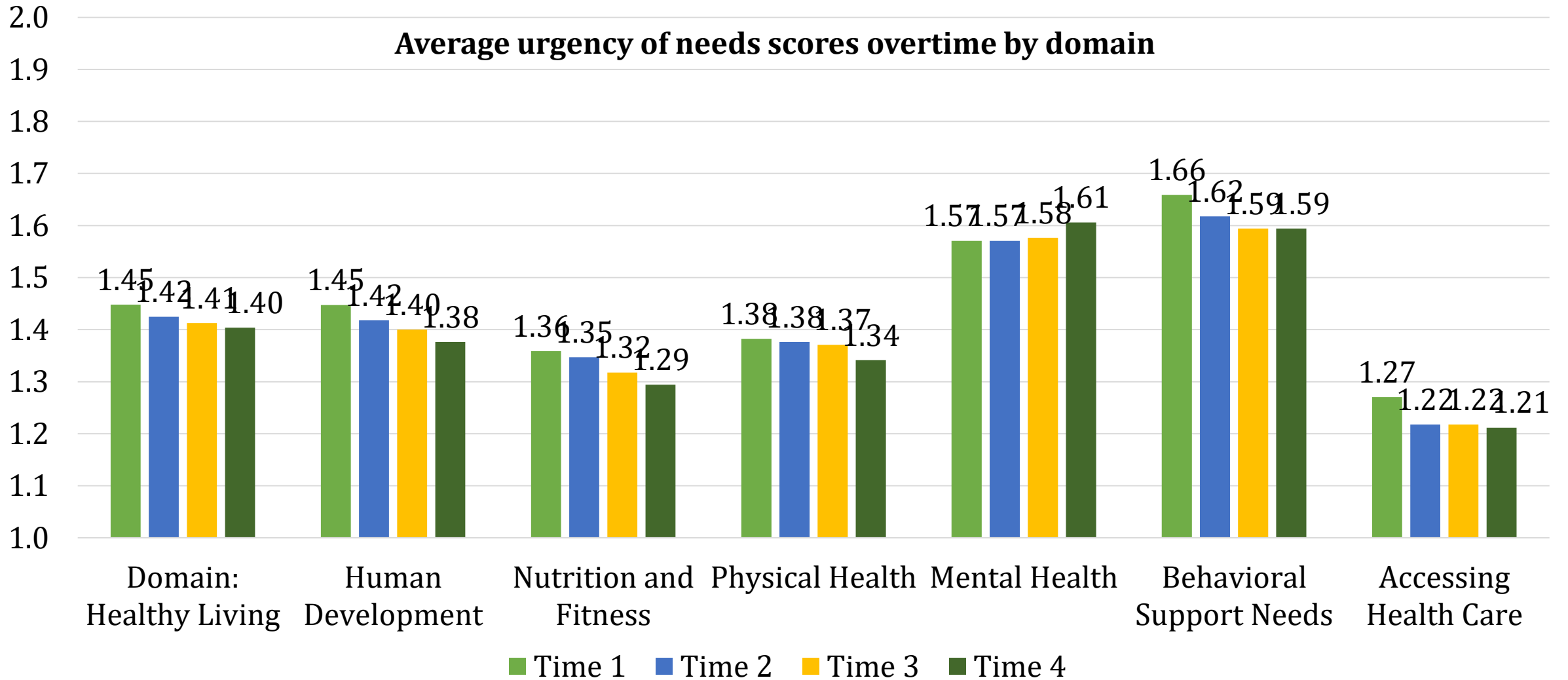
Average urgency of needs scores overtime by domain



Social and Spiritual

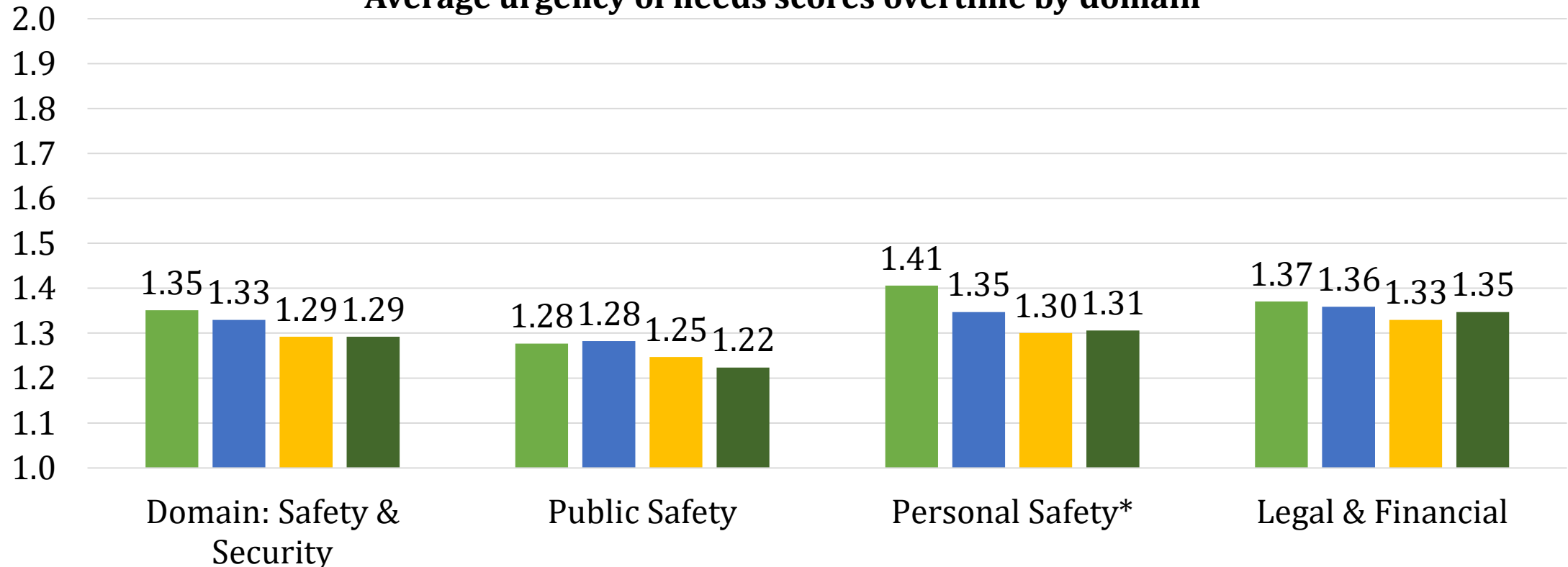


Healthy Living



Safety and Security

Average urgency of needs scores overtime by domain



* $p < .05$

■ Time 1 ■ Time 2 ■ Time 3 ■ Time 4

Personal Safety: All family members are safe at home. A plan and/or supports are in place to keep all family members safe and Person with disability is able to make decisions about personal safety and/or utilizes supported decision making.

Life Outcomes Progression Scale: Key Findings

- Participation in the *DD Family Support Program*
 - **Improves families' life outcomes**
 - **Significantly decreased** avg. urgency of needs ratings for 3 of 18 scale items from Time 1 to Time 4:
 - *Home Life* (Domain: *Daily Life and Employment*)
 - *Personal Safety* (Domain: *Safety and Security*)
 - *Daily Coordination* (Domain: *Daily Life and Employment*)
- Areas of least improvement from Time 1 to Time 4:
 - *Mental Health* (Domain: *Healthy Living*)
 - *Civic Engagement* (Domain: *Citizenship and Advocacy*)
 - *Legal & Financial* (Domain: *Safety and Security*)
 - *Leisure and Recreation* (Domain: *Social and Spiritual*)
 - *Housing* (Domain: *Community Living*)

Life Outcomes Progression Scale: Key Findings (cont.)

- Areas of greatest need at Time 1:
 - *Leisure and Recreation* ($M = 1.76$)
 - *Home Life* ($M = 1.71$)
 - *Behavioral Support Needs* ($M = 1.66$)
- Areas of greatest need at Time 4:
 - *Leisure and Recreation* ($M = 1.74$)
 - *Home Life and Mental Health* ($M = 1.61$)
 - *Behavioral Support Needs* ($M = 1.59$)