

# Your Voice Has Power

How research helps to tell the HI story

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# HI Global Registry Quality of Life

- There are surveys in the HI Global Registry (HIGR) to collect information about quality of life (one for caregivers and one for the person living with HI)
- The surveys cover a range of topics such as health, social support, school/work, and medical care, mostly on a subjective scale
- Quality life is an incredibly important area of research that helps to ensure adequate care and support and to measure how HI is impacting a family over a lifetime
- Other surveys such as diet and feeding also provide a information about the burden of the disease
- QOL is very family dependent, which is why it is important that everyone participates, and every voice is heard!



**Your  
family's  
experience  
with  
hyperinsulinism  
could help find a cure.**

Sign up for the HI Global Registry today at  
[higlobalregistry.org](http://higlobalregistry.org)

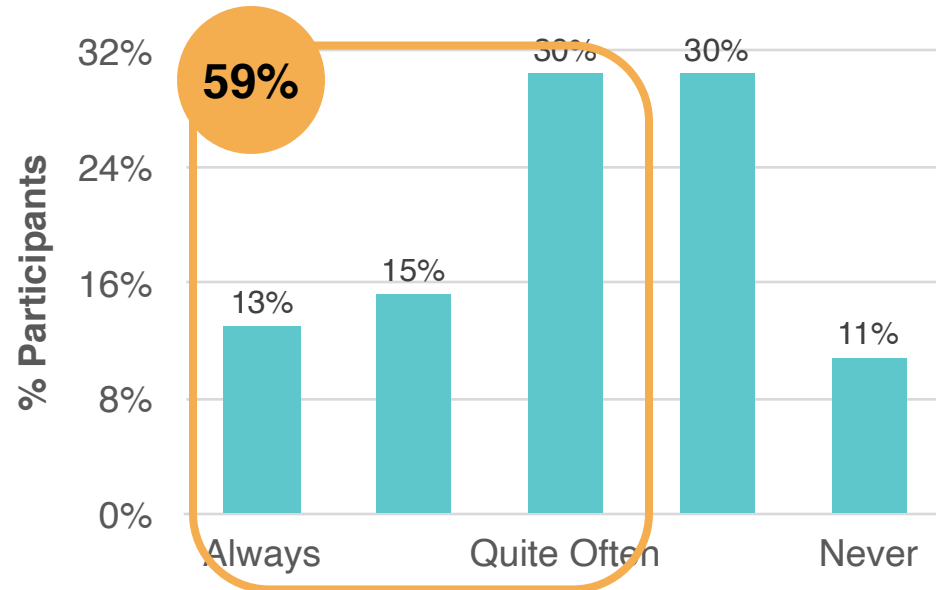
[higlobalregistry.org](http://higlobalregistry.org)



# Participant Perspectives



Do you feel that your life is ruled by your HI? (n = 46)

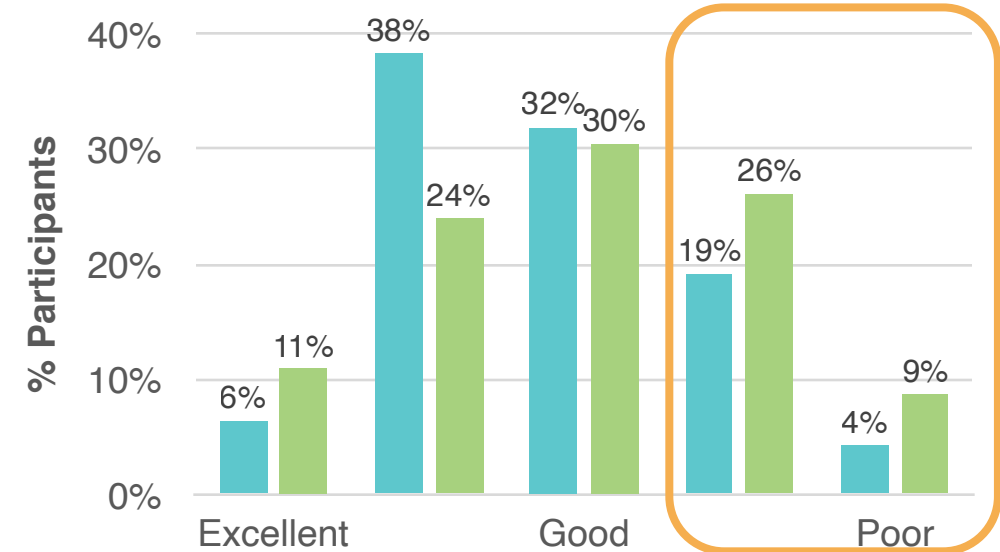


**Over half (59%)** of participants with HI feel that their life is ruled by their HI



How would you rate your:

- Physical health? (n = 47)
- Mental health? (n = 46)



- **1 in 4** participants rated their **physical** health as fair or poor
- **1 in 3** participants rated their **mental** health as fair or poor

“Participant” = person with HI

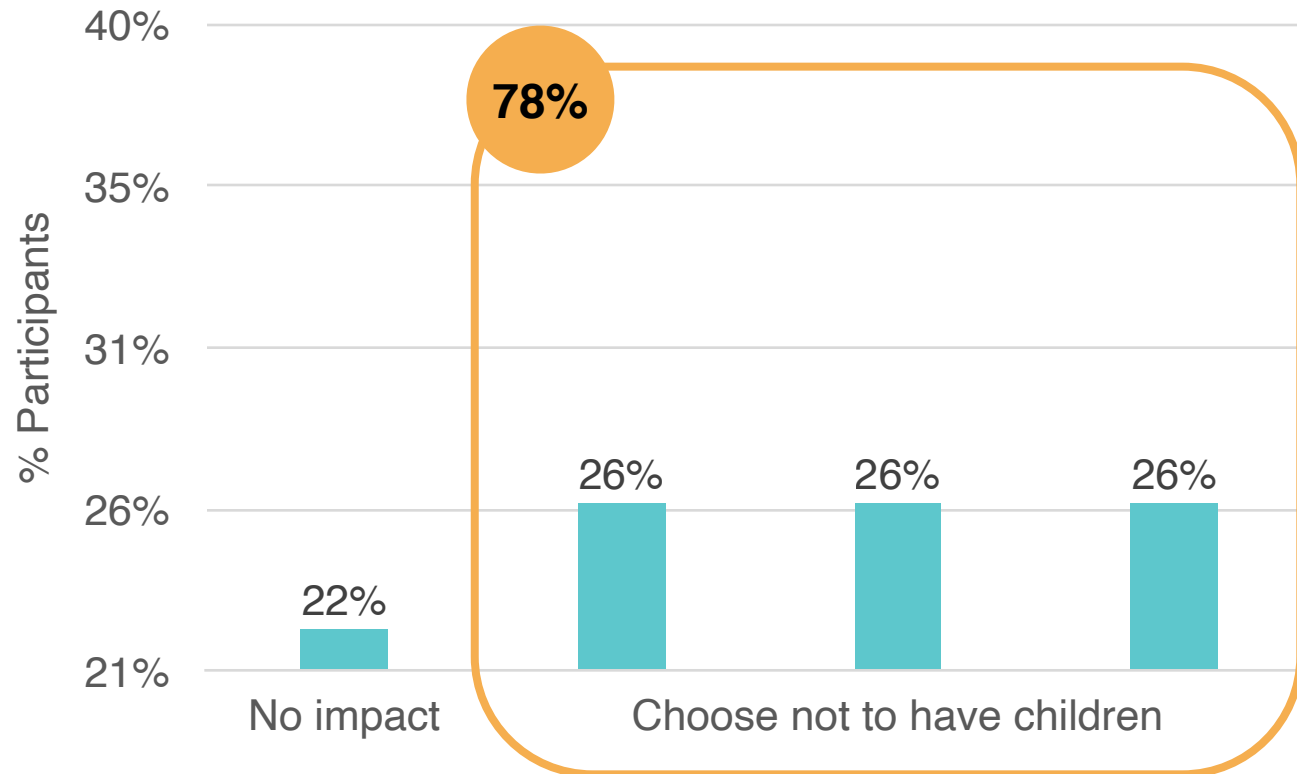
Participant QOL is assigned to all participants > 14 years old

# Participant Perspectives



## How has having HI affected your decision to have children? (n = 27\*)

\* Excludes n = 20 who responded "Not considered yet" or "Not applicable"



## HI impacted family planning for **3 in 4\*** participants with HI

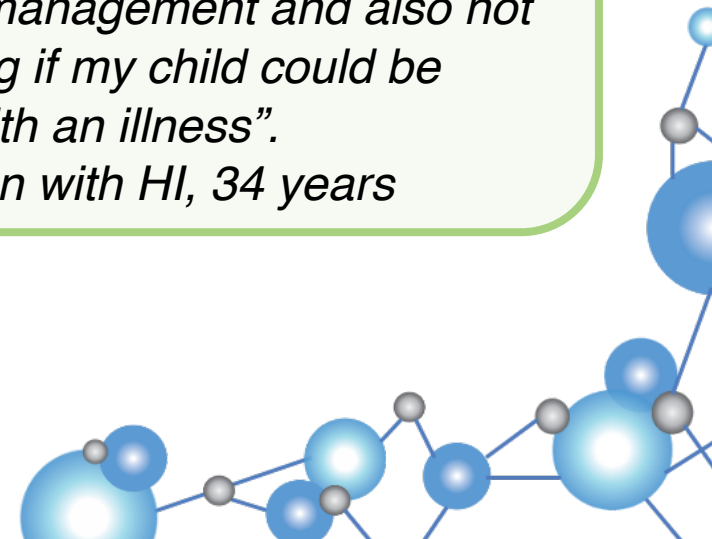
\* Includes those who selected "other" – complex question and defined response options didn't cover the nuances of their answer.



*"I feel uncertain about whether or not to have a child. Due to potential changes with my blood sugar management and also not knowing if my child could be born with an illness".*  
- Person with HI, 34 years

**"Participant" = person with HI**

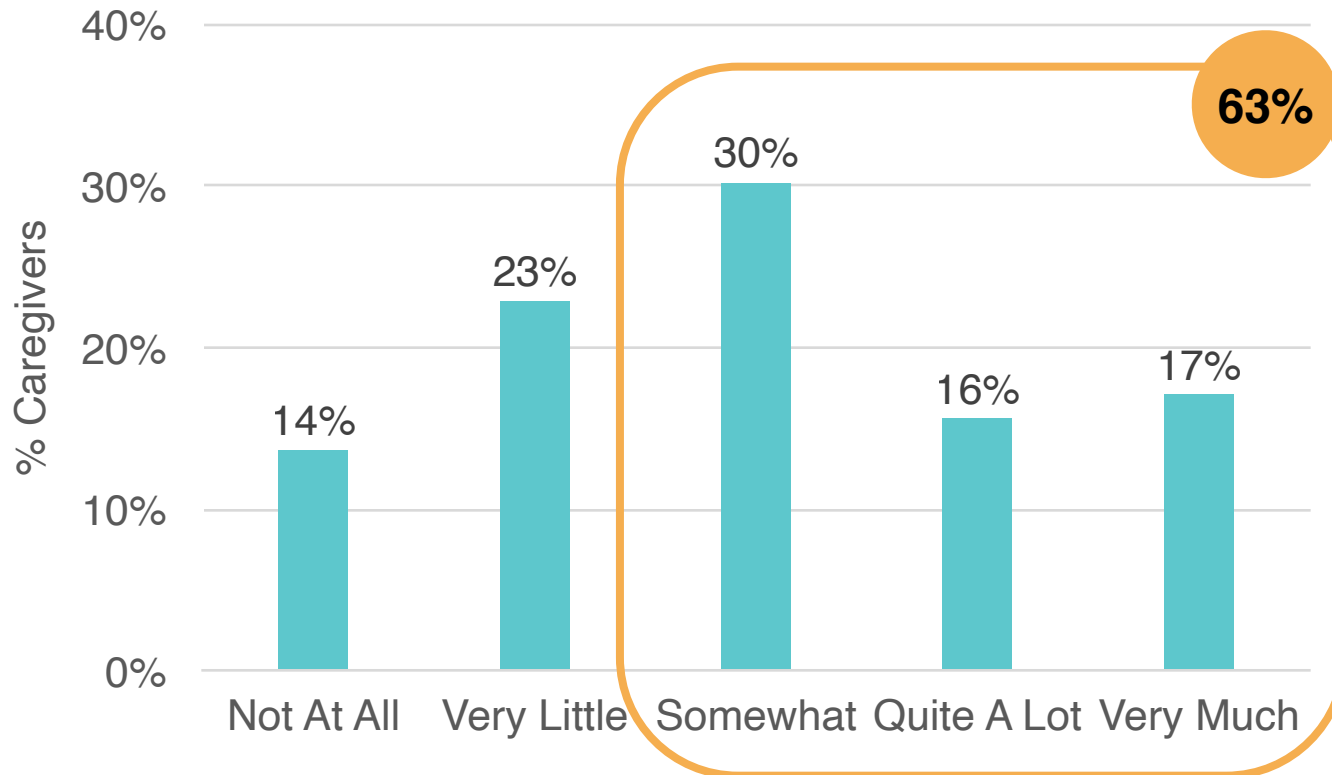
Participant QOL is assigned to all participants > 14 years old



# Household Financial Burden



Has your household income been negatively impacted due to the participant's HI? (n = 205)

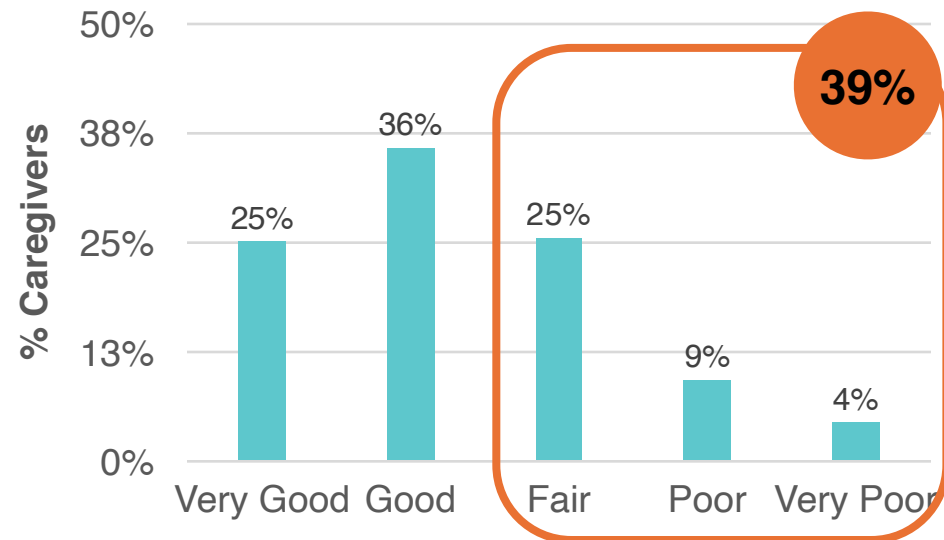


Almost **2 in 3** caregivers reported HI has had a negative impact on family finances

# Household Financial Burden



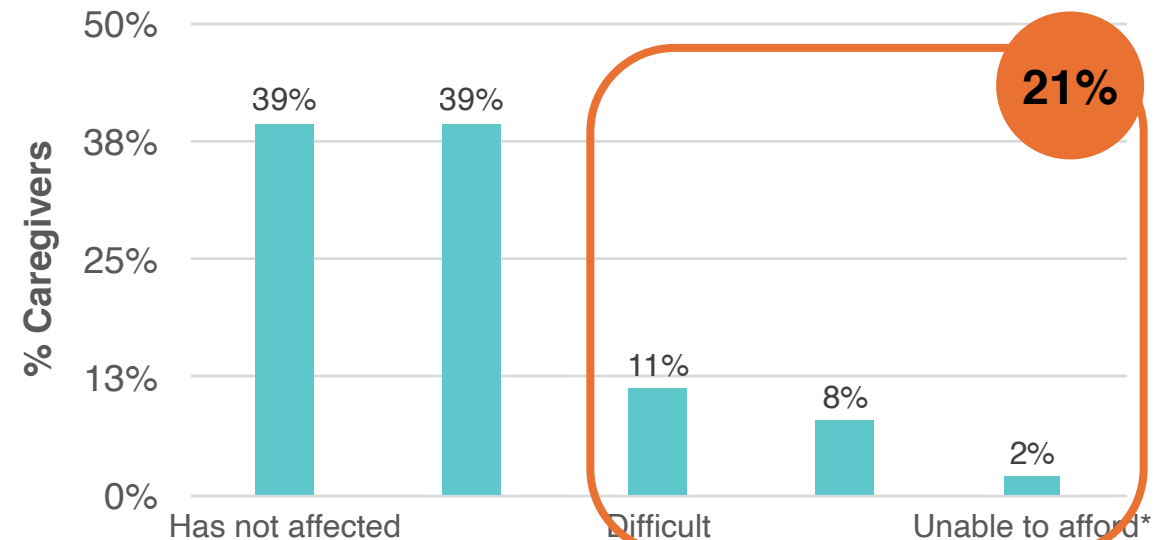
How would you rate your ability to pay for the costs associated with caring for the participant with HI? (n = 204)



**2 in 5** caregivers reported some difficulty paying for HI-related costs



How has caring for the participant with HI affected your ability to pay for household essential expenses? (n = 203)



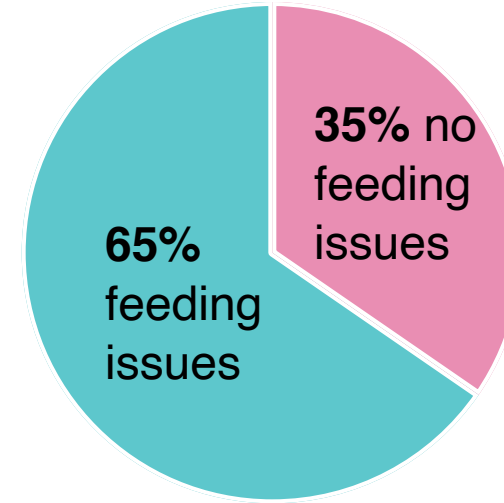
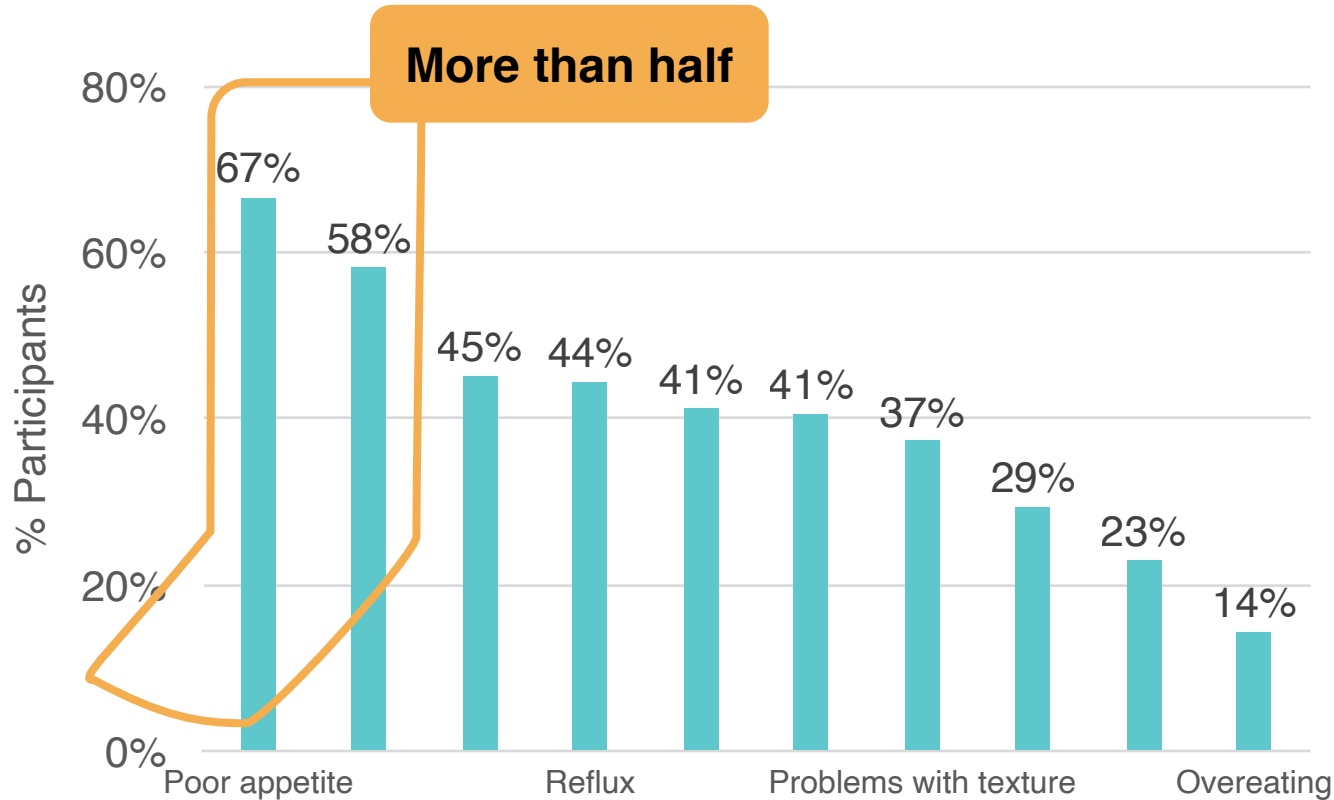
**1 in 4** caregivers reported some difficulty paying for household expenses

\* Even with financial assistance

# Feeding Issues



Has the participant experienced any feeding issues on a regular basis? (n = 237)



**Most** participants with HI have experienced feeding issues.

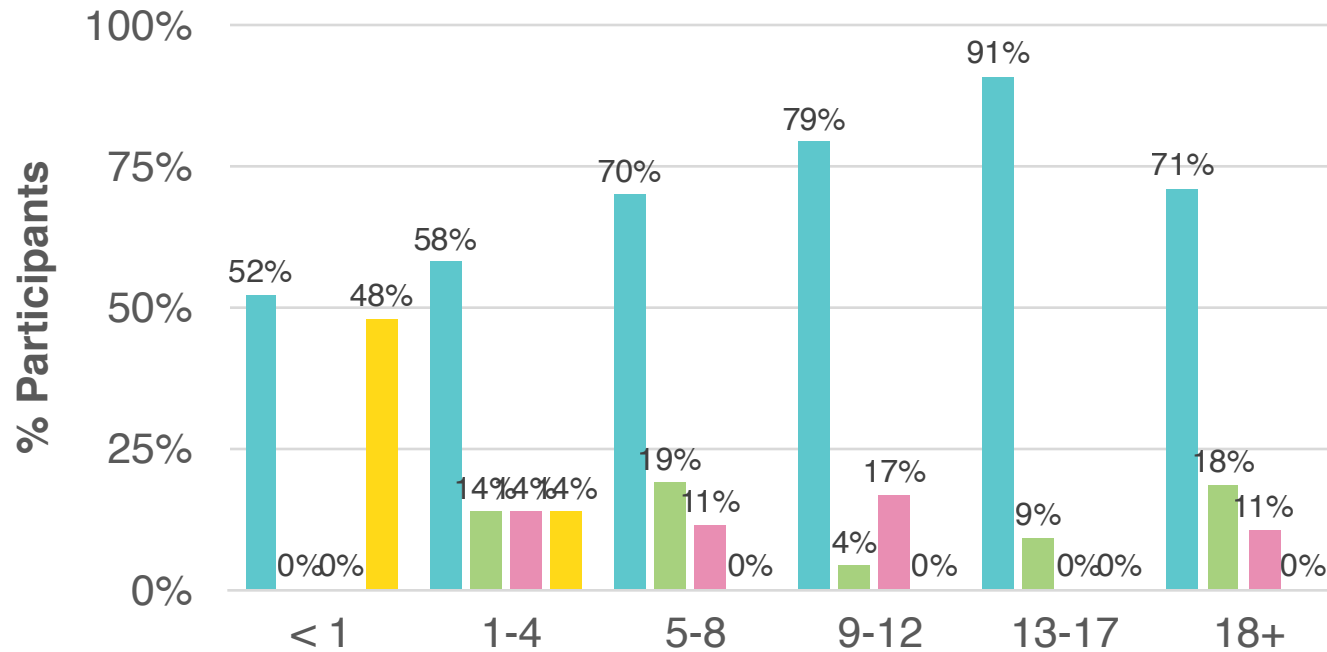


Most common issues include **poor appetite** and **refusing to eat**

# Comparison to Peers



Is the participant capable of performing most **self-care/hygiene behaviors** as peers of the same age? (n = 244)



- At peer level or above
- Variable
- Below peer level
- Unsure / Unknown

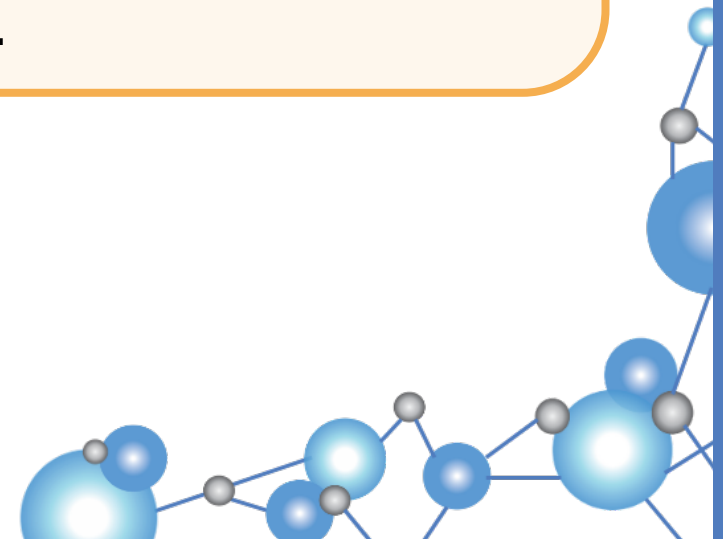
Participant Age (Years)

“Participant” = person with HI



Many younger children struggle to perform self-care/hygiene behaviors at peer level.

Most catch up as they get older, but **1 in 4** still have trouble by the **teen and adult years.**









# Comparison to Peers



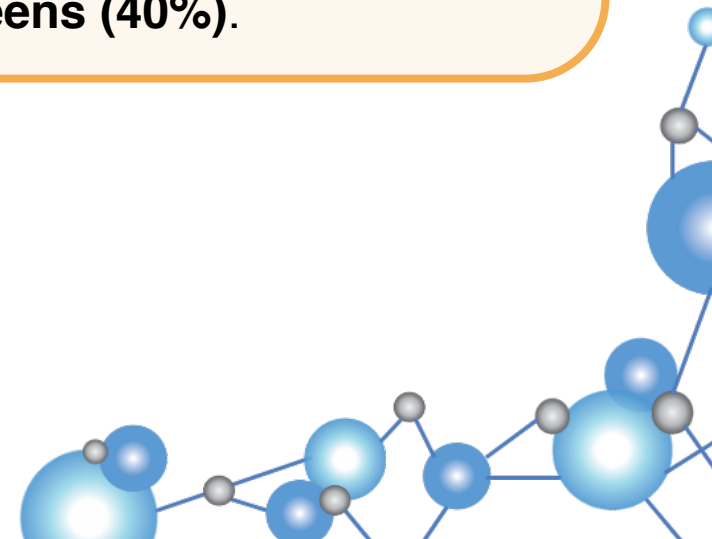
Is the participant capable of performing most **relationship behaviors** as peers of the same age? (n = 244)



Difficulties performing relationship behaviors are evident in about **30% of younger children** and become **more common in older children and teens (40%)**.

-  At peer level or above
-  Variable
-  Below peer level
-  Unsure / Unknown

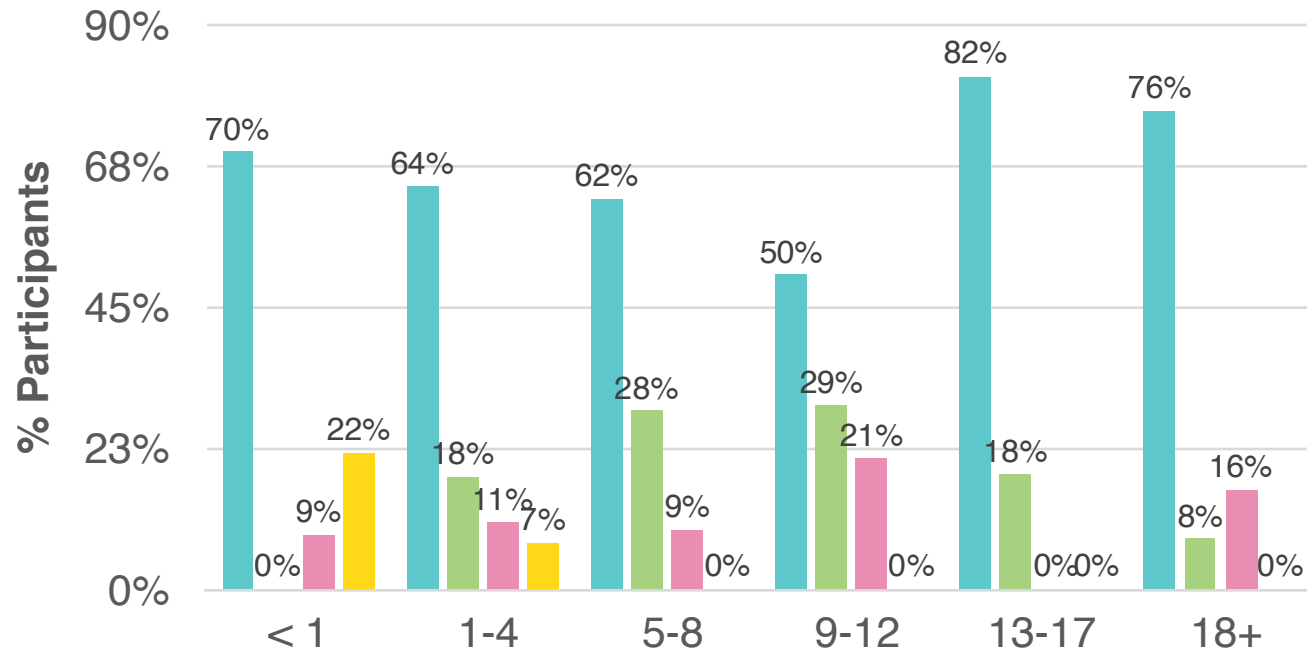
“Participant” = person with HI



# Comparison to Peers



Is the participant capable of performing most **cognitive tasks** as peers of the same age? (n = 244)



- At peer level or above
- Variable
- Below peer level
- Unsure / Unknown

Participant Age (Years)

“Participant” = person with HI



**30-50% of children with HI have trouble performing cognitive tasks at peer level, and problems persist in adulthood for some individuals.**

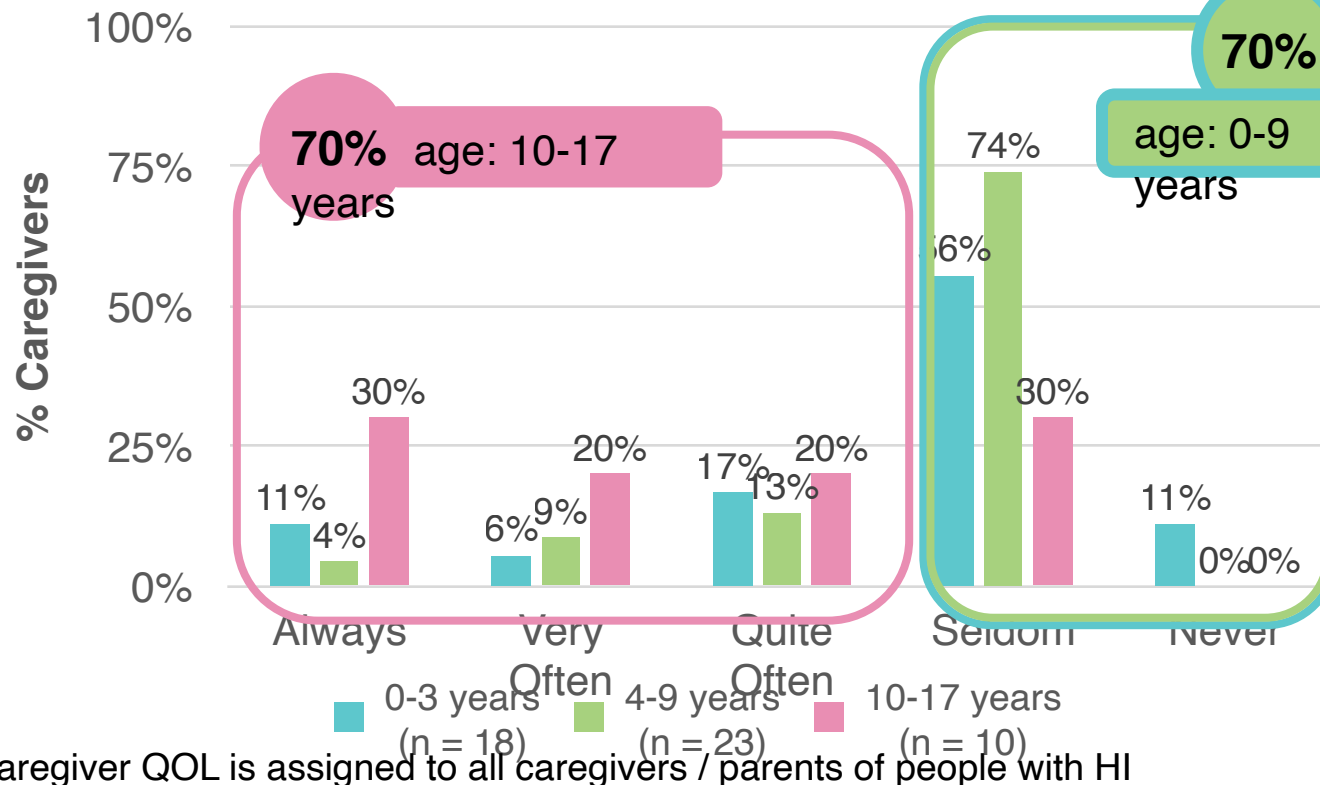
# Ability to trust others with the responsibility of care



Do you feel comfortable allowing others to care for the participant without you being present (i.e. babysit)? (n = 53)



Most caregivers of young children do not feel comfortable leaving participant with others, but caregivers of older children are more comfortable with this



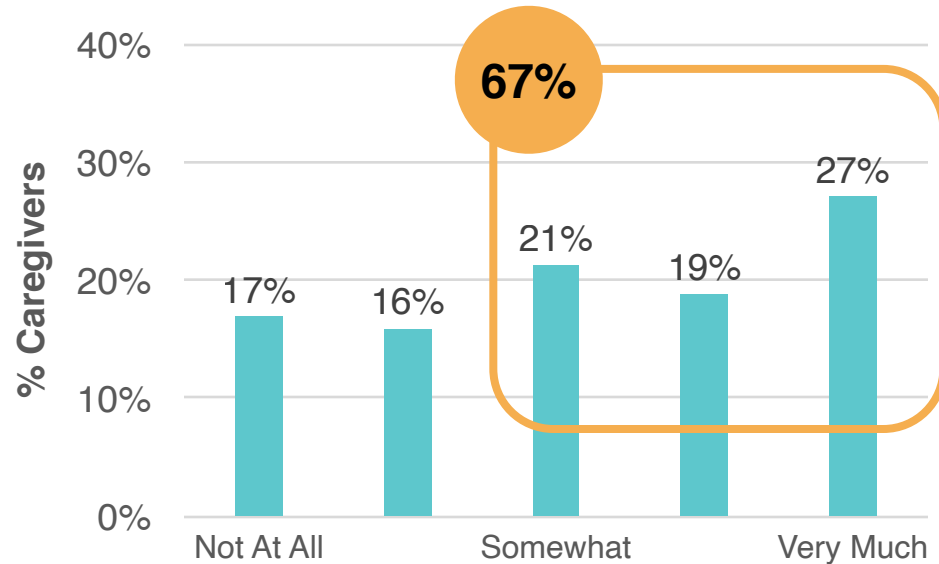
*"I take him with me most places, some people are afraid to babysit him and would even say that they prefer to babysit my 2-year-old daughter rather than him".*

*- Parent of a 4-year-old child with HI*

# Impacts on Caregiver Career



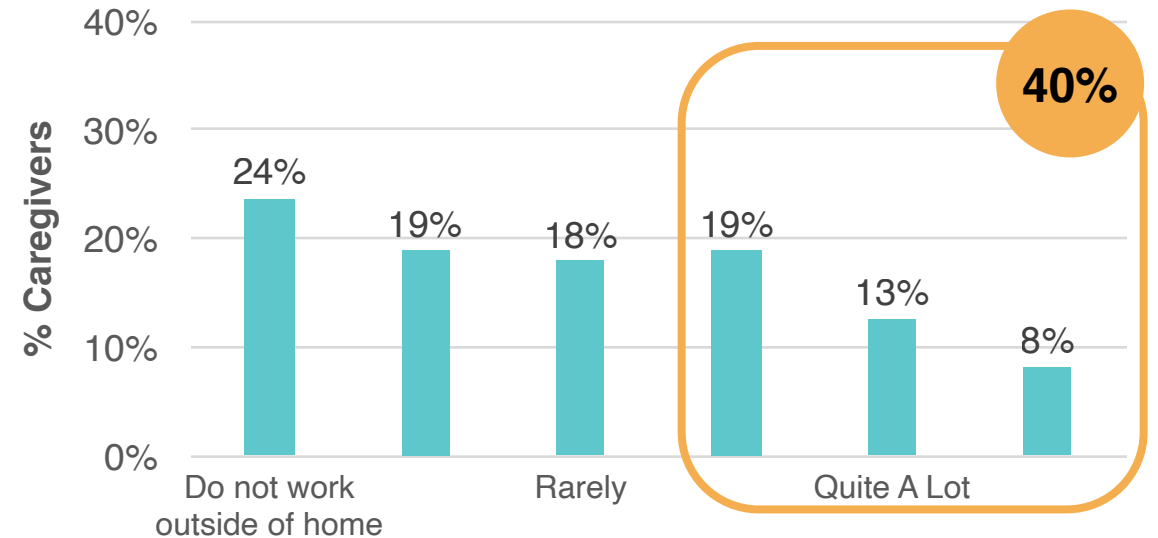
Have your work/career plans changed due to the participant's HI? (n = 207)



**2 in 3** caregivers reported their **career plans have changed** (for better or worse)



In the last year, how often have you missed school/work due to the participant's HI? (n = 207)



**2 in 5** caregivers reported they have **missed some school or work** due to participant's HI

# Emotional Impact of HI



**Do you worry because of your / the participant's HI?**

**Caregiver: n = 208**

**Participant: n = 46**



Caregivers report higher levels of worry than participants do

**“Participant” = person with HI**

Participant QOL is assigned to all participants > 14 years old.

Caregiver QOL is assigned to all caregivers / parents of people with HI

