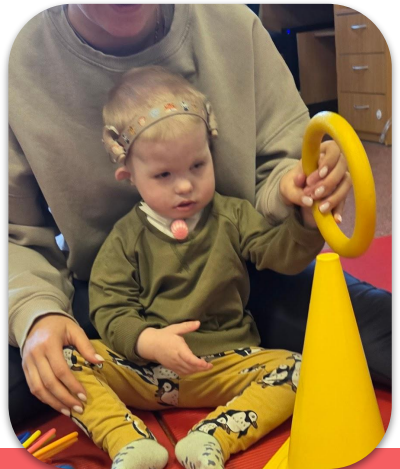
Personal experience raising a deafblind child in Lithuania

Tadas was born with the genetic Charge syndrome:

- He cannot breathe through his nose and mouth. He breathes through a special tube in his neck called a tracheostomy.
- He cannot swallow food, so he is fed through a special tube in his stomach, called a gastrostomy.
- His eyes have large, untreated vision-impairing lesions called colobomas.
- Born deaf, underwent bilateral cochlear implant surgery.

But he has:

- a family that loves him.
- personal care worker at home up to 240 hours/month.
- rehabilitation sessions 1-2 times a week.
- sessions with a deaf and hearing aid specialist once a week.
- doctor and nurse home visits as needed.



and he can:

- get up and out of bed independently.
- to crawl or walk while holding on to a desired object/activity.
- unhindered to explore their favorite activities, places as much as they want.
- to participate in a joint activity, a game.
- understand some gestures shown to him: mom, dad, brother, go, finished, come, sleep, home, yard,eat.

what else is needed

- specialists who can provide nursing and educational services at home
- home services that would allow parents to step back, but the child would remain in an environment adapted to them.
- Communities