

ANNUAL REPORT 2024

 OUR NORMAL

Shifting perspectives

Illustration

Content

Welcome

OUR NORMAL
ournormal.org
info@ournormal.se

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JENNY LINDSTRÖM BEIJAR
Parent & Founder

As we reflect on the journey of Our Normal I am filled with immense gratitude for the dedication and resilience of our community. Founded with a simple yet profound purpose—to connect families who have experience living with children with disabilities and special abilities – Our Normal has grown into a beacon of support, understanding, and empowerment.

As the founder of Our Normal, it brings me great pride to present our first annual report. This report not only celebrates our achievements but also sheds light on areas where we can strive for improvement. It is crucial for us to listen to the voices of our members, particularly parents, who provide invaluable insights into the challenges they face on a daily basis.

In this report, we will focus on five key areas identified by parents as in need of improvement: health, transport, home life, free time activities, and school. These areas are not just categories on a checklist; they represent the very fabric of our family's lives and the challenges

we encounter in navigating a world that often fails to accommodate our unique needs.

Through honest reflection and constructive feedback, we aim to identify gaps in our support systems and advocate for meaningful change. Our Normal is not just an association; it is a movement fueled by compassion, advocacy, and a relentless pursuit of inclusivity.

I invite you to delve into this report with an open heart and a commitment to action. Together, we can create a world where every child, regardless of ability, can thrive and find their place in society.

Thank you for being part of Our Normal's journey. Your support is not only appreciated but essential as we continue to champion the rights and dignity of every individual within our community.

Our normal

Our Normal is a community where families come together to find strength, support, and solidarity in the shared journey of raising children with disabilities and special abilities. Our Normal is run by parents who themselves have children with disabilities and special abilities.

At Our Normal Association, we recognize that there is no one-size-fits-all approach to parenting, and every family's journey is marked by its own set of joys, triumphs, and obstacles. Whether it's finding resources, sharing experiences, or simply connecting with others who understand, Our Normal Association provides a safe and welcoming space where families can find the support and encouragement they need to thrive.

Driven by the principles of inclusivity, compassion, and empowerment, Our Normal Association offers a range of services and programs designed to meet the diverse needs of our members. From online forums and support groups to educational workshops and advocacy initiatives, we are committed to ensuring that every family has access to the resources and support they need to navigate the complexities of raising a child with disabilities.

I remember how great it was to meet other parents who also had experienced different unpredictable life changes and who could relate to what I was talking about.

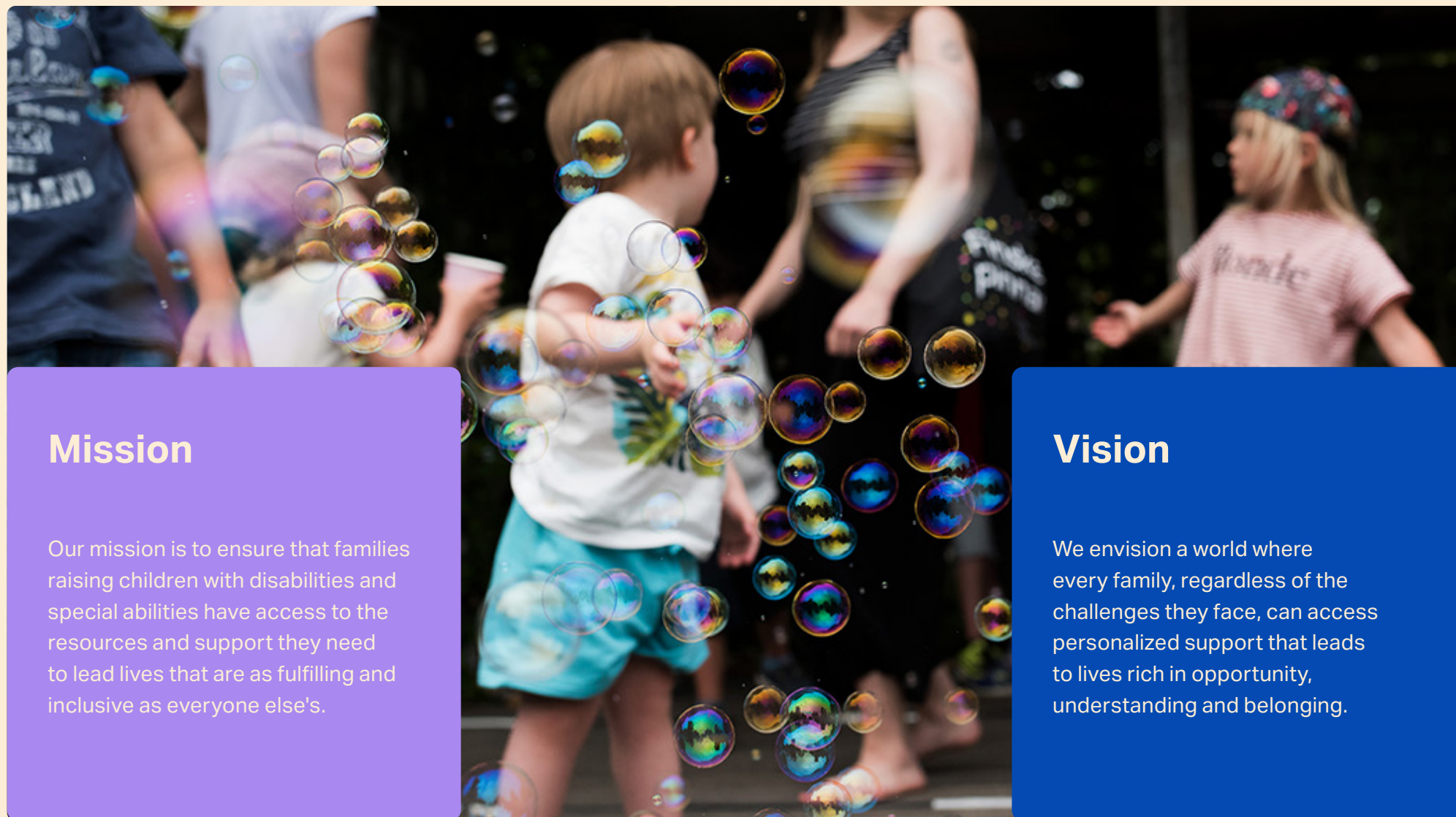
JOHANNA, MOTHER TO ELTON AND NOOMI

Design Lab

The Design Lab of Our Normal serves as a hub for creativity and problem-solving, where members and experts come together to address the unique needs and challenges faced by families with children with disabilities and special abilities.

Design can be a potent force for good, especially when it prioritizes inclusivity.

MARCO GUADARRAMA, design strategist and UX researcher at IKEA



Mission

Our mission is to ensure that families raising children with disabilities and special abilities have access to the resources and support they need to lead lives that are as fulfilling and inclusive as everyone else's.

Vision

We envision a world where every family, regardless of the challenges they face, can access personalized support that leads to lives rich in opportunity, understanding and belonging.

Through targeted research, design thinking, and community engagement, the Design Lab identifies areas for improvement and advocate to develop solutions that enhance the quality of life for our members.

In this year's annual report, we aim to shed light on five crucial areas that demand our attention and collective effort: health, transport, home life, free time activities, and school. Through the lens of parents who navigate these challenges daily, we will explore the hurdles they face and the opportunities for improvement that lie ahead.

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Join us as we delve into the realities of our community members, striving to create a world where every child, regardless of ability, can thrive and find their place in society.

15.
Free time activities

4.
Health

7.
Transport

12.
School

19.
Home life





Health

Navigating the healthcare system becomes a full-time job for parents of children with disabilities. From financial strains to coordinating care among different specialists, the journey is fraught with challenges. Advocacy becomes paramount as parents fight for their child's needs and rights.

Having contact with different doctors

Navigating the healthcare system can often feel like embarking on a labyrinthine journey for parents of children with disabilities. From the family doctor to specialists in various fields, each interaction is a vital step towards ensuring their child receives comprehensive care. But reaching out to different doctors isn't just about setting up appointments; it's about seeking out help and guidance for their child's well-being. Every call is a plea for support in a system that can often feel impersonal and overwhelming. It's about forging connections and building relationships with healthcare providers who hold the keys to potential breakthroughs.

Coordinating my child's healthcare feels like running a marathon with no finish line. Yet, every day I advocate fiercely for my child's needs, hoping for a system that truly supports us.

ANNA, PARENT OF EMILY

Coordination of care

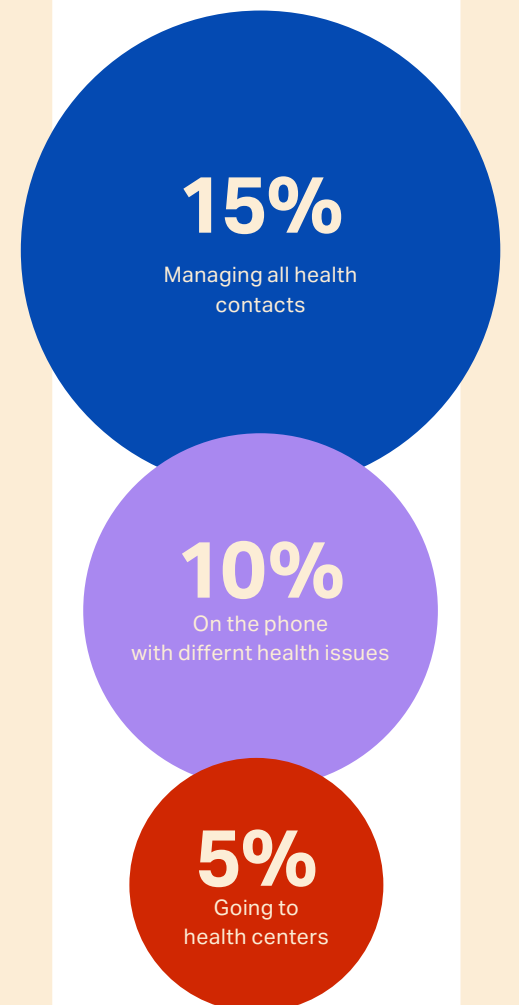
Coordinating care for a child with disabilities is like managing a complex puzzle with missing pieces. Parents

find themselves juggling appointments, medications, and treatments, all while trying to ensure that each healthcare provider is on the same page. It's a constant balancing act, but through careful planning and communication, they strive to create a cohesive plan that addresses their child's unique needs. From ensuring that medications don't interfere with each other to coordinating therapy sessions and follow-up appointments, every detail is meticulously organized to provide the best possible care for their child. Curabitur cursus egestas nulla, in pharetra nisi accumsan ac. Nulla facilisi. Praesent ullamcorper tincidunt maximus. Vestibulum in egestas enim. Ut mattis est ut felis hendrerit, sit amet egestas sem condimentum. Aliquam sit amet arcu eget felis vehicula vestibulum.

Financial strain, insurance policy

The financial strain of caring for a child with disabilities is a reality that many parents face. From the costs of medical treatments to the complexities of insurance policies, they are forced to make tough decisions to ensure their child's needs are met. It's a balancing act, but their resourcefulness and

TIME SPENT WITH HEALTH ISSUES (per week)



A WEEK IN A FAMILY'S LIFE:

HEALTH PERSPECTIVE

Monday

- ▶ Preparing for and attending swimming lessons with the child.
- ▶ Administering medication routines in the evening.

Tuesday

- ▶ Phone meeting with a psychologist.
- ▶ Managing medications.

Wednesday

- ▶ Phone meeting with a psychologist.
- ▶ Receiving a new prescription for glasses.
- ▶ Hospital visit to the eye clinic.

Thursday

- ▶ Communicating with healthcare providers about medication and appointments.
- ▶ Planning and coordinating schedules around medical appointments & medication.

Friday

- ▶ Receiving updates from the school regarding personnelc availability.
- ▶ Planning for meetings with school personnel to discuss the child's health needs.

Saturday

- ▶ Administering medical routines, including medication management.
- ▶ Visiting the optician for the child's new glasses.

Sunday

- ▶ Continuing with medical routines.
- ▶ Participating in activities with the child, accommodating their health needs.

determination allow them to navigate these challenges with resilience and strength. They are constantly evaluating their options, exploring financial assistance programs, and advocating for policy changes that could alleviate the burden on families like theirs. It's about ensuring that financial constraints don't stand in the way of their child's health and well-being, fighting for access to affordable care and support every step of the way.

Advocacy for the kids needs.

Advocating for their child's needs isn't just a choice; it's a responsibility that parents take on with determination and resolve. Whether it's fighting for necessary treatments, navigating insurance hurdles, or ensuring access to specialized care, advocacy becomes a part of their daily routine. They speak up, they push back, and they never stop fighting for what their child deserves—a chance at a healthy and fulfilling life. It's about being their child's fiercest advocate, championing their rights and ensuring they receive the support and care they need to thrive.

Being involved in their health/see behaviours

For parents of children with disabilities, being involved in their child's health goes beyond just attending medical appointments. It's about being attuned to their child's needs, observing their behaviors, and noticing even the subtlest changes that could indicate a potential health issue. It's about being their child's first line of defense, vigilant and proactive in ensuring their well-being. Whether it's noticing a change in appetite, a new symptom, or a reaction to medication, parents are constantly monitoring and assessing their child's health, ready to take action.

What if...

Digital tools were a priority for children with disabilities, reducing the need for meetings and travel?

Children with disabilities visited one main place, and specialists came to them?

A child patient's numerous contacts were flagged within the healthcare system, ensuring all staff are aware and can support the family accordingly?



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A week in a life

Throughout the week, there's a consistent focus on managing the child's medical needs alongside other responsibilities. These include attending appointments, managing medications, and ensuring the child's comfort and well-being in various settings.

4 contacts

Balancing medical meetings strains parents' busy schedules.

6 doctor's visit

Children's anxiety and fatigue disrupt daily family life during medical procedures.

? uncertainty

Confusing medical communication frustrates parents, causing ongoing uncertainty.

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Time spent with health issues (per week)



Home life

Balancing the demands of everyday life can feel like a juggling act, but for parents of children with disabilities, it often becomes an all-encompassing journey. Every aspect of home life, from routines to family dynamics, is influenced by the unique needs of their child.

Provide emotional support for the whole family

In the journey of caring for a child with disabilities, emotional support is not just essential for the child but for the entire family. Parents often find themselves navigating through a spectrum of emotions – from worry and stress to moments of joy and hope. Siblings may also require attention and reassurance as they witness the challenges faced by their brother or sister. Creating a nurturing environment where emotions are acknowledged and shared helps the family cope with the ups and downs of their journey.

Balance sibling dynamics

Sibling dynamics in families with children with disabilities can be complex. Siblings may experience a range of emotions, from love and empathy to frustration and jealousy. Balancing the needs of the child with disabilities while nurturing healthy relationships among siblings requires open communication and understanding. Parents strive to create opportunities for bonding and shared experiences, ensuring that each child feels valued and supported within the family unit.

Balancing the needs of my child with disabilities while maintaining a sense of normalcy for the entire family is a constant challenge. From adapting our home environment to providing emotional support, every day brings new hurdles.

RON, PARENT OF CECILIA

Social isolation

Social isolation is a common challenge for families with children with disabilities. Limited accessibility to public spaces and activities, coupled with societal misconceptions, can lead to feelings of exclusion and isolation. Parents often find themselves navigating through a maze of barriers to ensure their child's participation in community events and social gatherings. Building supportive networks and advocating for inclusive spaces are vital steps in combating social isolation and fostering a sense of belonging for the entire family.

Adapting the house for the child's needs

Adapting the home environment to accommodate the unique needs of a child with disabilities is a continuous process. From installing ramps and

A week in a life

Home life for this family is a dynamic and demanding journey filled with a multitude of tasks and responsibilities. There is a concerted effort to maintain routines, provide tailored support, and ensure the well-being of every family member.

logistic

Challenges intensify as parents juggle appointments, pickups, and deliveries.

everyday routines

Evening and morning routines demand careful planning amidst family responsibilities and tasks.

sybling dynamics

Providing emotional support for the whole family.



handrails to creating sensory-friendly spaces, parents undertake various modifications to enhance accessibility and comfort. These adaptations not only promote independence and safety but also play a crucial role in fostering the child's development and well-being within the familiar surroundings of home.

Having home support

Home support services play a pivotal role in easing the daily challenges faced by families with children with disabilities. Whether it's assistance with personal care tasks, respite care to alleviate caregiver stress, or therapeutic interventions tailored to the child's needs, home support services provide invaluable support to the entire family. Access to reliable and compassionate support professionals enables parents to navigate their caregiving responsibilities with greater confidence and peace of mind.

Negotiating for flexible work hours to be home

Balancing caregiving responsibilities with professional commitments can be a daunting task for parents of children with disabilities. Negotiating for flexible work hours allows parents the flexibility to attend medical appointments, therapy sessions, and address the immediate needs of their child. Flexible work arrangements not only promote work-life balance but also empower parents to prioritize their family's well-being without compromising their career.

What if...

Communities established regular support groups where families with children with disabilities could share experiences and resources, fostering a sense of belonging and understanding?

Employers offered flexible work-from-home options specifically tailored to the needs of parents caring for children with disabilities, easing the burden of balancing work and home life?

There were neighborhood initiatives that provided respite care for families with children with disabilities, offering parents much-needed breaks while ensuring their child's well-being in a supportive environment?



Municipalities actually was fined substantially for not following the law and give the families the support they have the rights to receive.

Someone was appointed to be in charge of the SIP-meetings; to follow up and make sure things progress.



Looking into the future, how could we live life like anyone else?

Parents could decide themselves who the main person to contact would be every time a new contact is established.

Children with disabilities had one main physical space to visit - and not 12. Specialist could visit that centre to the largest extent possible.

