

POV Community Engagement & Education

DISCUSSION GUIDE



He's My Brother

a film by Cille Hannibal and Christine Hanberg

www.pbs.org/pov



HE'S MY BROTHER

Christine's brother, Peter, experiences his world through touch, smell, and taste. Now that Peter is 30 years old, his family is having trouble finding the proper care for his multiple disabilities. Told through Christine's eyes, *He's My Brother* explores how the family works to assure him a dignified life once the parents are gone—and Christine's uncertainties about one day becoming his primary caregiver.

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This guide is an invitation to dialogue. It is based on a belief in the power of human connection and designed for people who want to use *He's My Brother* to engage family friends, classmates, colleagues, and communities. Conversations that center disability, learning, and identity can be difficult to begin and facilitate, but this guide is meant to support you in sustaining growth-oriented conversations. In contrast to initiatives that foster debates in which participants try to convince others that they are right, this document envisions conversations undertaken in a spirit of openness in which people listen actively and share divergent viewpoints with care and respect. We hope this discussion guide will inspire people with varying degrees of knowledge and experience about these topics to enter the conversation and hopefully stay in the conversation in order to impact change and awareness.

The discussion prompts are intentionally crafted to help a wide range of audiences think more deeply about the topics in the film. Rather than attempting to address them all, choose one or two that best meet your needs and interests. *And be sure to leave time to consider taking action.* Planning next steps can help people leave the room feeling energized and optimistic, even in instances when conversations have been difficult and/or uncomfortable.

Participants

Peter, a 30-year-old man who was born deafblind as a result of prematurity, lives with his parents in Denmark. He is frequently challenged and frustrated by not being able to communicate what he wants, thinks, or feels. He has also been identified as having autism spectrum disorder, which sometimes occurs in children who are visually impaired and deafblind.

Jonna is Peter and Christine's middle-aged mother and the primary caregiver for Peter. She struggles to turn over caregiving responsibilities to her daughter and worries about what will happen to both her children in the future.

Jorgen, Peter's father and advocate, tries to pass on information about advocating for services and planning for Peter's future to his daughter, Christine. He, too, worries what the future will bring for his son and the rest of his family.

Christine is Peter's twenty-something sister who is struggling to figure out her role in her brother's life as an adult.

Grete, a parent of an adult child who is deafblind and a major support to Jonna, provides information and encouragement to help Jonna and the family move forward in planning for the future individual and as a nation.

BACKGROUND INFORMATION**What is the life experience of someone who is born deafblind?**

Though this film is unlikely to trigger a negative response from your audience, it is our desire that the audience see the individual who is deafblind in a positive light. The life of an individual who is deafblind, even from birth, is not darkness and despair, though it has significant challenges. Our tendency is to pity these individuals, rather than recognizing our shared humanity or valuing the bravery they exhibit in living life. Getting to know individuals who are deafblind can fundamentally change our perceptions about what it means to be human. Educators believe that these individuals have much to teach us about living if we take the time to enter their world fully.

Many people who are deafblind are born with either vision or hearing intact, or both senses intact, and then lose full use of these senses later in life. This is referred to as “acquired” deafblindness. Though they have similar challenges, their experiences as people who once had full use of these senses make a great deal of difference in their ability to develop communication and to function independently in the world. Our focus in this film is on individuals who are born deafblind.

Individuals who are born with limited or no sight or hearing as a result of some complication of birth, trauma, or genetic syndrome experience the world and life from a unique perspective that depends primarily on the senses of touch, smell, taste, and proprioception (the body’s ability to sense its location, movements, and actions in the joints, tendons, and muscles). This presents barriers in developing foundational concepts and language skills that allow them to have quality interactions with others and to understand the world around them. These impairments make it difficult to understand many of society’s rules about personal space and behavior in public.

Autism spectrum disorder is a neurodevelopmental condition that sometimes co-occurs in individuals who are visually impaired or deafblind. Research suggests it may occur more frequently among individuals with certain genetic defects, prematurity, and pathologies that impact the central nervous system. This and other physical and medical challenges may impact the individual’s ability to cope with certain sensory information. This further increases the challenges of interaction with the environment and people.

Not knowing when and what things are going to happen in the future is very stressful for individuals who are deafblind. This is why [specialized calendar systems](#) are so important for them. These calendars, first developed by Dr. Jan van Dijk, help the individual begin to grasp concepts of time and anticipate or recall events. Calendars help provide a structure to teach the serve-and-return interactions we call conversation, as well as components of language.

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The symbols used in a calendar (real objects, parts of objects, tactile symbols, braille, print) help the user develop a form to use in communicating with others. They also help the user share a focus with another person, a topic around which to make comments, ask questions, recall events, and anticipate the future. This reduces anxiety and stress, often the cause of disruptive or self-abusive behaviors.

Contrary to common belief, deafblind individuals live lives filled with sensory information that they are able to take in through their senses. They love and are loved by their families. With support they can enjoy and contribute to their communities. These individuals also have much to teach us about life, such as living at a different pace and seeing the world from a different perspective.

The field of deafblind education, focusing specifically on children who are born with deafblindness, is in its infancy. Best practice strategies for children with congenital deafblindness (including those with additional disabilities) began in the late 1960s as the result of the rubella epidemic.

Because this is a low-incidence disability, the general public has almost no knowledge of how to approach or interact successfully with individuals who are deafblind, especially individuals who are dependent on tactile information for communication and interaction. This results in these individuals receiving little or no programming that might lead to development of higher levels of learning or communication.

There are only a few teacher training programs for teachers of the deafblind, and there is little credentialing for this specialized profession in the United States. Special education teachers, teachers of the deaf and hard of hearing, teachers of the visually impaired and blind, and paraprofessionals may have almost no instruction in deafblind education strategies. Canada faces similar challenges, but has addressed support needs for these individuals through the use of interveners—one-on-one paraprofessionals trained in deafblindness. The United States has only recently begun to recognize this role in educational and rehabilitation settings and has very limited resources for paying or training these individuals. Worldwide this support is limited or nonexistent.

In the 2020 national deafblind child count, the U.S. federal registry of all individuals aged birth to 22, there were 10,483 individuals identified as deafblind. It is estimated that about 41% of this number have additional disabilities in cognitive, medical, and physical areas of development. There is no count done to identify children who were born with severe vision and hearing loss, like Peter, though prematurity is the leading cause of deafblindness.

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In Alaska, there were only 18 individuals identified as deafblind, and in California there were 986. This means that many, if not most, school districts do not have any children who are deafblind. Since many state residential schools for the deaf or blind, serve only a few children who are deafblind with multiple challenges in congregated settings, training cannot be centralized to develop specialized skills for staff addressing the unique needs of students like Peter. The vast majority of individuals who are deafblind in the United States are in public school settings with staff who have little or no experience or training to adequately address the educational needs of these children.

Most states have schools for the blind or deaf that offer training and information services, and there are also a number of national support resources, such as the National Center on Deaf-Blindness. Recently, Open Hands, Open Access (a series of online training modules) was created for the National Center on Deaf-Blindness by a diverse group of experts in the field. These training modules are available free to families, professionals, and paraprofessionals who want to learn more about supporting individuals who are deafblind.

There are currently many best practice strategies for educating individuals with deafblindness, both individuals who were born deafblind and those who became deafblind later. For the first time ever, many resources describing these strategies are available worldwide through web-based venues. Still, the mentor support needed to help staff who try to serve these children on a day-to-day basis does not exist.

Intensive, life-long support

These individuals have intense support needs in all areas of life, and such support is typically provided by their families. Parents generally take on the responsibility, but in some cases grandparents or foster parents fill that role.

Because services from government agencies, meant to provide for individuals who are deafblind as adults, are often very limited and difficult to access, families face uncertain futures that cause stress on the entire family system. There are pitifully few residential placements and support services in the United States and elsewhere in the world that can address the intense needs of an individual who is congenitally deafblind.

Parents also worry about what the responsibility for the child who is deafblind will do to their other child(ren) if they assume caregiving responsibilities in the future. This is true whether the individual who is deafblind lives with their sibling or in some other arrangement. Most parents fear that their children will not be well cared for and may even be abused in any setting outside the family home.

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Though some programs provide funding to staff who work in the family's home, these in-home support workers are often difficult to find and keep because of low wages. Any training they receive about deafblindness often has to be provided by a family member.

Impact of deafblindness on the family

Humans are never entirely independent, but rather are interdependent creatures who struggle with balancing our own needs and desires with those of the individuals we love. Anyone who has experienced caring for a loved one through a major health crisis, supporting someone going through difficult emotional times, or simply doing the day-in-day-out types of care that parents offer their children understands this struggle.

Whether it is our family of birth or the family we create, family is family. We look to those we love to support us, and we desire to give support to them. This relationship is at the heart of what we call "family." For most of us, the caregiving roles change over time, and intensive support needs don't last indefinitely. However, if a family is providing support to an individual who is congenitally deafblind, this full-time responsibility continues for the life of the individual.

The usual progression of children leaving home and creating their own families or of children caring for aging parents becomes much more complicated. Financial planning, for example, requires specialized legal expertise in order not to jeopardize access to government support like Medicaid and Social Security Disability Insurance. Guardianship for medical or financial decisions is necessary after age 18 if the family wants to maintain a voice in what happens with their son or daughter. Creating an active life with rich social and emotional connections in the community can be challenging as the individual who is deafblind ages and leaves school. This can lead to depression and other mental health challenges for the family and the individual who is deafblind.

A parent's responsibility for a family member with disabilities often begins at birth and does not end until the child or the parents die. Often the primary caregiver becomes so enmeshed mentally and physically with their child, they cannot imagine life without that child directly in their care. As parents age, they sometimes feel it would be better for the individual who is deafblind to die first because they fear what will happen to the child when they are gone.

As the individual who is deafblind ages out of school programs, support services become even more limited. The young adult is at home and the parents have even less time to take care of personal and other family needs. Resources that are available at one point, such

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as day programs or respite care, may suddenly disappear. This places additional stress on the primary caregiver, who must also take on the role of services manager and advocate.

Most rehabilitation services accessed by adults with disabilities focus on independent living and employment, which is typically not possible for individuals who are congenitally deafblind because of their intensive support needs. There are only limited funds (usually through Medicaid in the United States) that can be used by the family to provide respite care, in-home services, and/or housing in group living or institutional settings. These programs are often underfunded and have long waiting lists. Almost none are designed to address the unique needs of individuals who are congenitally deafblind.

In recent years, families have collaborated to create support using government funds, grant funds, and money raised through their own fundraising activities. One such place in Texas is [Touch Base Center for the Deafblind](#), which provides day programming for individuals post-graduation.

Siblings of the child who is deafblind often want to assume at least some responsibility for their sibling. This is especially true when the nondisabled sibling is younger. As the sibling ages and begins to make a life for themselves, however, they often feel this responsibility to be unfairly burdensome, especially if they decide to have children of their own. Most struggle to know what their roles should be in caring for the future needs of their brother or sister who is deafblind. They may feel great love, and at the same time, not want to give their lives over to their brother or sister in the same way their parents have. Their parents may have difficulty releasing their caregiving role to the nondisabled child or moving the child out of the parents' home. This often creates tension between siblings and the parents.

As parents age, they usually become exhausted, mentally, physically, and emotionally. For many families the biggest support they have is a connection through a family organization to other families of children who are deafblind. The issue of isolation and the importance of families connecting with other families cannot be stressed too much. Families of individuals who are deafblind often feel as if they are all alone, that no one else has a family member like theirs. This is why helping families to connect with other families is critical.

There are a number of support organizations for families of individuals who are deafblind (including siblings), but making these connections often depends on information provided by professionals who may not be aware of these resources. In many cases, the family learns more about resources that are available through their own research than do most of the educators, medical professionals, social workers, and early intervention specialists who work with the child.

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Connecting to other families changes the quality of life for the family and the individual. Family-to-family support helps in areas of advocacy, quality of life decisions, access to resources, and support during critical transition times (e.g., movement from home to school-based services, transition to inclusive settings, planning for adult life). Other families of individuals who are deafblind have a degree of legitimacy and expertise that most professionals simply can't provide. In the United States, the [National Family Association for Deaf-Blind](#), [Project Sparkle](#), and the [CHARGE Syndrome Foundation](#) are some of the support resources helping to make that family-to-family connection.





STARTING THE CONVERSATION

We encourage you to view the film with your audience before discussing these points. It is important to frame the discussion in positive terms when talking about the life of someone who is deafblind. We strongly believe that we are more alike than different and hope you will discover part of our shared human experience in watching *He's My Brother*.

What does it mean to be congenitally deafblind?

Deafblindness takes different forms based on the age of onset of the sensory losses, the degree of the loss, and the type of loss. Various combinations of these losses result in a very diverse population of deafblind people. All of these types of deafblindness have impact on communication, social and emotional development, concept development, relationships, and movement for travel and spatial awareness.

This film deals with an individual who was born with a great degree of vision loss and hearing loss as a result of being born prematurely. His experience of the world and his interactions with the world are heavily dependent on senses of touch, taste, smell, and proprioception. He does not know the world in the same way most people do, even those who became deafblind after an age when many concepts about the world were established and language was beginning to develop. Still, Peter's life is filled with information coming through his other senses.

You may want to watch these clips again before discussing:

(4:45-10:41 Importance of smell and touch)

(34:58-36:43 A day at the beach)

All of an individual's senses work together eventually, though people are not born with them fully integrated. Sighted-hearing people don't typically pay as much attention to other senses when recalling a location or event. Without sight or hearing, other sensory information defines experience. In fact, research shows that areas of the brain that typically process sight and sound are reallocated to process other sensory information, especially touch, when an individual is deafblind.

Touch receptors are located throughout the body and provide a wide range of information, including pain, temperature, shape, weight, texture, density, pliability, and elasticity. Some receptors are dedicated to our active touch (when we touch something) and some to passive touch (when something/someone touches us). We also have touch receptors in tendons, muscles, and joints that help us know where our bodies are in space and how we are moving.

Smells trigger powerful emotional memories, largely because the brain regions that process smells, memories, and emotions are intimately connected. The capacity to smell allows us to track water and food, alerts us to dangers such as fire, helps us find a mate, enables us to identify people and things, and impacts our emotions. Since COVID, many of us have learned how taste and smell are connected.

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Taste receptors register four flavors—sweet, salty, sour, bitter. Recently savory, or umami, has also been identified as a unique receptor. Taste, like smell, is evocative of strong emotions since in our evolution, a bitter or sour taste might signal poisonous plants or rotten protein-based food. Sweet and salty flavors signal the likelihood of a food rich in nutrients. This is why a bad taste can evoke nausea or vomiting. It is our body's way of alerting us to something that might kill us!

Here are some activities you may use to start a discussion:

- Think about a trip to the beach, the mountains, or the shopping mall. Describe your experience.
 - Do you recall details about the experience that are related to your senses of touch, taste, smell, or proprioception? What are they?
 - How would that experience differ if you had never been able to see or hear?
 - What might startle or frighten you about the experience?
 - What might you find especially interesting?
- Close your eyes and, if possible, plug your ears. Now only pay attention to what you feel through touch.
 - What do you feel without moving?
 - Do you feel air blowing on your skin, pain in a joint or muscle, the scratch of a label in your clothes?
 - Are you standing or sitting? What is moving in or on your body?
- Now use your other senses to explore some of the things around you without using vision or hearing.
 - What can you tell about an object when you simply hold it without squeezing or rubbing it?
 - What can you tell about an object when you rub it with your fingers?
 - What about squeezing an object?
 - Does the object have a particular taste or smell?
- Touch is very emotional and very intimate. Without looking at your partner, take turns exploring each other's hands.
 - How would this experience be different if you did it with a stranger?
 - How would you feel if you touched legs instead of hands?
 - How do you know the difference between appropriate and inappropriate touch?
 - What if you were dependent on someone else to take care of or help take care of intimate bodily functions, such as toileting, bathing, grooming?

DISCUSSION QUESTIONS

Why are relationships critical for humans and human development?

“Growth-promoting relationships are based on the child’s continuous give-and-take (‘serve and return’ interactions) with a human partner,” according to the National Scientific Council on the Developing Child, 2004 paper “Young Children Develop in an Environment of Relationships.” Research has shown that interactions with others are nearly as important to our survival as food, water, and shelter. Building good emotional and social skills begins even before birth in the relationship formed between baby and parent. It rapidly extends to other caregivers within the family and over time to others in the child’s community. Without quality relationships, humans are at great risk for developing both physical and mental health issues.

The art of forming relationships is not easily learned when you are born deafblind. Many people, sometimes including parents, don’t know how to connect with an individual who has many physical, sensory, medical, and cognitive challenges. New parents may have never known anyone with a disability before, and it is very likely they never met a congenitally deafblind child before their child was born. Most parents of congenitally deafblind children find out their child has problems only after the child is born. Their child may spend weeks or months in a neonatal intensive care unit. Siblings and other relatives may not meet the child for a very long time. Home life is greatly disrupted. Grandparents are saddened for their children, as well as for their grandchildren. Some grandparents and other friends or relatives may not feel comfortable around the child. Relationships in the community often disappear as the parents stop participating in their usual social circles because of the demands of caring for their child and because of their grief.

You may want to review these clips before discussing the questions below:

(32:46-34:57 Decision to live)

(18:24-20:48 Waiting to ride)

Peter was born premature and spent an extended period in the hospital in an incubator. He was attached to a feeding tube for a time. The impact of an extended stay in the hospital is enormous on both the infant and the parents.

- What type of stress would you imagine Peter experienced as a result of his prematurity? How do you think this impacted his ability to bond and interact with his parents and others?
- How did this experience and his deafblindness impact his parents’ ability to bond and interact with him?

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- How did the stress of a premature baby with so many challenges impact Peter's parents? What do you think Peter's parents felt about having a child who was deafblind versus the child they dreamed they would have when Jonna was pregnant?
- Why do you think it was so much easier for Christine to interact with her brother when they were younger? Have you ever felt embarrassment or frustration with a family member's behavior? What did it make you feel about yourself?
- Many people feel a loss of connection in our world. How do you reach out to make connections with others every day?

Crucial to all relationships is the ability to communicate with one another. It is our primary way of sharing who we are and what our life experiences have been. In Andy Weir's novel, *Project Hail Mary*, an astronaut encounters a new life form and must learn to communicate with it in order to save humanity. What ensues are a series of situations that require the astronaut to figure out a way to communicate with a being whose entire life experience is completely different from his own. In fact, he cannot be in the same atmosphere as his alien buddy. Despite their differences, the two space heroes find a way to communicate and form a deep relationship with each other.

Typically developing children begin to communicate by observing and referencing their bodies, real objects, people, animals, and actions primarily through vision and hearing. The adult or child points or gazes at things, offers an object, or does something with their body, and the adult names it. Through repetition, the label takes on meaning. Over time concepts are enriched and become more specific. For example, all men cease to be called "daddy" and become refined into "grandpa," "mailman," or "dancer."

Communication with a child born deafblind requires a number of things: trust, shared experience, good observational skills, a willingness to follow the child's lead, turn-taking interactions, and opportunities to repeat experiences in a predictable way. Without vision or hearing, touch replaces the way joint attention is attained between the adult and child. For the world to become meaningful to the child there is a need for physical access and some concepts (color, an elephant) defy touch. Paying attention to the way the child communicates with their body requires close observation and a great deal of guessing. If the child's subtle communication attempts are missed, the child may simply give up trying to have an interaction.

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Individuals who are born deafblind do communicate, but their communication is very idiosyncratic and requires others to enter their world, rather than the other way around. When misunderstood, individuals who are deafblind experience the same frustrations we all face when people miss our point. Sometimes their behavior clearly communicates this frustration and distress.

You may want to review these clips before discussing the questions below:
 (29:50-31:17 Bodily-tactile connection)
 (31:30-32:45 Distressed)

Imagine you encounter a group of people who are talking about something you are completely unfamiliar with, using words you don't understand. They also don't seem to understand you or give you a chance to contribute to the conversation.

- How would you respond if you could not find a way into that conversation?
- Have you ever had an experience in which you tried to explain something to another person and were unable to make them understand? What happened? What happens to your voice? Do you use gestures? Have you used other tools for communicating, such as pictures and maps?
- How do you feel when people don't listen to you or seem to ignore what you are trying to tell them?
- What would you do if you continually felt no one was listening to you or understanding what you were trying to communicate?

How do we support each other and individuals who have disabilities?

We like to think of ourselves as independent, and our success depends on our ability to take care of our own needs. Yet, in reality, none of us are truly independent. We rely on service and support from a community of paid and unpaid providers to handle things like fixing our cars, making our clothes, helping us with spiritual pursuits, even finding life-partners. We value most highly in our lives the people who we consider to be "there for us." Yet most of us do not require the same intensive support that an individual like Peter and his family do.

Finding support for all individuals in our society is not easy. Sometimes we don't know what is needed and sometimes we are hesitant to offer support that is not requested by the individual. We build systems to address needs, but these systems sometimes fail because they are not tailored to the needs of the individual. One thing we have all learned as a result of COVID is how interdependent we are on this planet. Charities and social agencies are good, but they let us be removed from the human experience of connection. Providing support is most rewarding when it boils down to one human helping another human.

DISCUSSION QUESTIONS

You may want to review these clips before discussing the questions below:

(21:42-24:52 Conversation about advocating for services)

(40:54-47:38 Home alone)

Think about the support you have in your life that lets you accomplish all you need to accomplish. Some of the support you buy from people or businesses (e.g., mechanic, hairdresser), some is provided by people who live with you or who are close friends, and some might come from people you work with or who are in your community.

- What support do you receive from your family? Government agencies or programs? Friends or colleagues? Community members?
- Which services do you pay for? Which are free?
- If you were a person who was deafblind, how do you think you would get all your support needs met?
- What ability would you have to choose the support you receive and how you receive it?
- What experience related to giving or receiving support has meant the most to you in your life?

How frequently do you interact with people who are significantly disabled? What would hold you back from forming a relationship with these individuals?

What could you (or we as a society) do to become more open to and engaged with people who are deafblind, especially those who are congenitally deafblind?

- What barriers do you face in meeting individuals who are deafblind?
- What ideas do you have for overcoming these barriers?
- In what ways might you provide support?
- What type of support do you think an individual who is congenitally deafblind might offer you?

In your family or your parents' family, how supportive are family members of each other?

- Has that support changed as the family members age?
- If you have siblings or other relatives of your generation, what role do you play in each other's lives?
- If you have lost a sibling, what has their absence meant as you get older?

How would you feel if you were responsible for a sibling after you were both adults?

- What would you find challenging?
- What would bring you joy in the experience?
- Do you think it would impact the way you interacted with them?
- Would it be easier to care for an elderly parent than for a sibling?

DISCUSSION QUESTIONS

OPTIONAL ACTIVITY: REWATCHING SCENES FOR COMMUNITY REFLECTION

The following scenes highlight some important aspects of Peter's and his family's experiences. As an optional activity, you may choose to rewatch the scenes described below and reflect on them with your community. What questions emerge? What does each particular scene teach you?

Humans with unique challenges

When people think of someone who is deafblind, they often think of Helen Keller, a brilliant woman who became deafblind at the age of 19 months. Helen had already learned many important concepts about the world, social interactions, and the beginnings of language development before she lost her vision and hearing. In this film we meet Peter, who was born deafblind as a result of prematurity. Unlike Helen Keller, he has not had good vision or hearing since the beginning of his life. His knowledge of how the world works has been constructed through his senses of touch, smell, taste, and proprioception.

Though some people imagine deafblindness means living in a silent and dark world, Peter's world is rich in sensory information. Like all human beings, he has life experiences that evoke a variety of feelings. Some things bring him joy, and other things frustrate or startle him. He remembers things, events, and people like anyone else, but these recollections are through the way they feel or smell or taste. Looking at this clip, we see examples of Peter using touch, smell, proprioception, and taste to understand where he is and what is happening and to recall favorite people in his life. **(4:45-10:41 Importance of smell and touch)**

Individuals like Peter are human beings first and foremost, but they face unique learning challenges and require intensive support throughout their lives. Communication challenges and access to information in general can lead to an individual becoming distressed or frustrated. Parents and family members often become interpreters for their children and attempt to communicate what they are thinking to others as we see in this clip. **(10:42-15:50 Trip to the grocery store)**

This responsibility to serve as the primary support for a child often sets up one of the parents to become "the expert." When others try to step in to provide support, releasing that role to another is very difficult for both parties. In the film we see this as one of the primary areas of tension between Jonna and Christine. **(14:13-18:21 Christine and Jonna talk)**

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Challenging society's rules

Most human beings learn social rules and appropriate behaviors incidentally, by observing others. Because individuals who are deafblind lack access to this type of incidental information, they typically need systematic instruction in social and emotional skills, part of the [expanded core curriculum for students with visual impairments](#). The lack of knowledge about societal norms and rules can cause problems and frustration for both the individual who is deafblind and those unfamiliar with ways to interact or grasp their differences. It is difficult for most of us to understand how long it takes to learn concepts and skills without the benefit of vision and hearing, as we see during the interaction between the stable staff and Jonna.

(18:24-20:48 Waiting to ride)

Lifelong advocacy

In this next film segment **(20:50-21:41 Dedicating your life)**, Christine asks, “What does it mean to dedicate your life to someone?” She has witnessed firsthand all that her mother and father have been required to learn and how they have fought to ensure that Peter has a good life. She recognizes that her mother sacrifices her own life to do this and is unwilling, as Peter’s sister, to follow her mother’s example. Christine’s father, Jorgen, shares how difficult their life has become, especially since the closure five years earlier of the daycare center Peter attended. The only respite Jorgen and Jonna now have is when Christine takes Peter. Jorgen shares the reams of paperwork they have accumulated from various attempts to get services and a placement for Peter. This, unfortunately, is what parents in the United States and other countries deal with throughout their child’s life, but especially after the child leaves public education at the age of 22. **(21:42-24:52 Conversation about advocating for services)**

Finding support for caregivers

Individuals who are deafblind and their families are also just living their lives like everyone else. We see, in the next clip, the family enjoying the hot tub and being together. **(24: 53-26:43 Hot tub snowy day)** Despite their enjoyment of time with each other they feel isolated because they aren’t connected to other people in Denmark who have a family member like theirs. The family’s best support comes from other families they have connected with through a family support organization for blind and deaf individuals in Norway. Siblings and parents benefit from sharing their experiences and learning from the experiences of other families like theirs.

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Grete, mother of Tormod, who is also deafblind, has become a very special source of support for Jonna and the family. She has been able to create a situation for Tormod where he lives in his own house with paid support staff caring for him there. **(26:44-29:25 A day with Grete)** Jonna feels they are a long way from having that security for Peter. She talks about how enmeshed she is with Peter, both physically and psychologically, because of the unique need to touch in all their interactions. She becomes quite emotional thinking about that level of bodily-tactile interaction disappearing from her life. **(29:50-31:17 Bodily-tactile connection)** After all the years she has spent caring for Peter, he has almost become an extension of her own body.

When communication fails

During a family outing in the winter woods, we see a brief clip of what can happen when Peter becomes distressed. No one is certain what is upsetting him, but Peter becomes very aggressive with his father, Jorgen, who tries to keep him away from a campfire. One of the many challenges of providing support to an individual who is congenitally deafblind is trying to understand what is upsetting them so they can be helped to recover from their distress without hurting themselves or others. As the parents age and the child grows bigger and stronger, this can put both parents and their adult child in danger. **(31:30-32:45 Distressed)**

Decision to live

The film interjects a clip of Peter as a newborn, obviously very fragile, spending most of his time in an incubator. **(32:46-34:57 Decision to live)** Jonna talks about how she and Jorgen struggled with all the medical interventions to keep him alive, wondering if they were going too far to save his life. The advancements made in medical technology and treatments in the last 50 years mean that more and more babies who once would not have been able to survive are surviving. When a decision was made to reduce these interventions at some point, Jonna says, the decision to live was ultimately made by Peter.

Experience of the sibling

In the next clip we see Peter, Christine, and Jonna at the beach. (34:58-36:43 A day at the beach) Peter has a unique way of approaching the water. Perhaps he is smelling the water or is able to see the sunlight sparkling on its surface. No one knows for sure whether a little bit of vision remains for Peter. Christine and Jonna think he is funny, perhaps wanting to pray as he puts the towel on the ground. Is it possible that he is recalling sitting on a towel at the beach during a previous trip or requesting that they sit down on the beach for a while?

DISCUSSION QUESTIONS

This scene points out one of the challenges sighted-hearing people face, especially when they don't know an individual's history. Peter is obviously thinking or recalling something, and it is only through intense observation and a great deal of conjecture that we can attempt to understand what his world is like. As one of our deafblind experts once said, we are called to "notice and wonder" when interacting with these individuals—something that might make interactions between all humans better.

At home again, Christine and Jonna reflect on the impact of having a sibling with disabilities. **(36:39-39:33 Did you ever think what would happen to me?)** When Christine was young she was "a natural," as her mother says, in her interactions with Peter. But when she started going to school, she realized that her family was "different" and that she had more responsibilities for her brother than other children did for their siblings. You can see the anxiety she is feeling when she asks her mother about expectations for becoming her brother's guardian. While parents hope that the nondisabled child will step into their role, at the same time they worry what this will mean for their nondisabled child's future. After all, they are not parents only to the child with deafblindness.

We transition to scenes of Christine and Peter together. Christine reflects on her current relationship with Peter, calling him "an anchor around my legs, dragging me down so I can hardly breathe." Still, she loves him and deeply wants to help him.

In a discussion with a friend, Christine seems to have reached a conclusion about her role in Peter's future. **(39:33-40:53 Coming to a decision)** She resolves always to be a part of his life, but feels strongly that he needs to live in his own house with support staff and not with her—something she hopes can be arranged very soon, before her parents die.

As a first step in her resolve to support both her brother and her parents, Christine arranges for Jonna and Jorgen to have a four-day holiday in Amsterdam, while she stays at home with Peter. Her parents, especially Jonna, are reluctant to leave her alone with Peter, but eventually agree to go on the trip.

Peter does not respond well to his parents' departure, becoming angry and overturning furniture when they leave. In the next scenes, Christine finds ways to comfort and support him in his parents' absence by offering favorite toys and letting him have one of his father's jackets. **(40:54-47:38 - Home alone)** Does Peter think his parents are gone forever, like his grandmother? As the weekend progresses, we see that Jorgen and Jonna are able to enjoy this time away, and Peter begins to enjoy his time with Christine as well.

Committing to the future

One of the final scenes takes place at Peter’s 30th birthday party. **(47:40-49:36 Happy birthday to you)** Peter is enjoying the festivities, smelling the champagne, laughing, and enjoying his meal. Christine rises to read a letter to Peter in which she recalls their past together. She speaks of his bravery: “Every step you take is a step into the unknown.” She goes on to talk about what the future will bring and how we, as humans, should not be limited by or fear the unknown because “together we are brave.” She states the ways she will continue to be in his life and give him the gift of her time: “time with me, time to hang out, time to go out, time for ice cream at the lake, time for roller coaster rides, time to visit future homes, time when Mom and Dad are gone, many, many, years from now, and time to be Uncle Peter one day.”

As the film comes to a close, we see the family visiting a carnival. **(49:37-50:54 - On this ride together)** Christine and Peter are together on a carnival ride while Jonna and Jorgen look on from the sidelines. This seems like a metaphor for their future life together. As the ride twirls and tilts, the two siblings, seated close enough to share the thrill of the ride, are still separate enough to bump into each other regularly.

Sources

Center on the Developing Child. “Young Children Develop in an Environment of Relationships.” <https://developingchild.harvard.edu/resources/wp1/>

Deafblind International, <https://www.deafblindinternational.org/>

Henry Ford Health. “Why Smell Is Important: The Role Your Nose Has in Helping You Make Decisions.” <https://www.henryford.com/blog/2021/08/why-smell-is-important>

Kate Moss Hurst, “Some Things to Learn from Learning Through Touch,” SEE/HEAR, Spring 2005. <https://education.mn.gov/mdeprod/groups/educ/documents/hiddencontent/bwrl/mdyw/-edisp/mde060168.pdf>

Mental Health Foundation. “Relationships in the 21st Century: The Forgotten Foundation of Mental Health and Wellbeing.” <https://www.mentalhealth.org.uk/sites/default/files/2022-06/MHF-Relationships-21st-Century-Summary-Report.pdf>

National Center on Deaf-Blindness. <https://www.nationaldb.org/contact-us/> National Center on Deaf-Blindness. “(2022).

National Library of Medicine. “How Does Our Sense of Taste Work?” December 20, 2011. <https://www.ncbi.nlm.nih.gov/books/NBK279408/>

How does our sense of taste work? Nordic Welfare Centre. “Deafblind Field.” <https://nordicwelfare.org/en/disability-issues/the-deafblind-field/>

Perkins School for the Blind. “Deafblindness Resources.” <https://www.perkinselearning.org/scout/topics/deafblindness>

Texas Deafblind Project., <https://www.txdeafblindproject.org>

ADDITIONAL RESOURCES

DEAFBLIND EDUCATION AND FAMILY SUPPORT**For a deeper dive**

Are you fascinated by what you have learned so far? Here are some additional resources you may want to explore to learn even more about deafblindness.

The [Texas Deafblind Project](#) has information on [deafblind Interaction](#), [educational strategies](#) for individuals who are deafblind, including those who are congenitally deafblind, [video interviews and lectures](#) from experts in the field of deafblind education, as well as [publications about aspects of deafblindness](#).

Some other resources that might be of interest to people seeking more information include:

- [Deafblind International](#).
- Linda Hagood. *Better Together: Building Relationships with People Who Have Visual Impairment and Autism Spectrum Disorder (or Atypical Social Development)*. (Austin: Texas School for the Blind and Visually Impaired, 2008).
- Barbara Miles, "[Talking the Language of the Hands to the Hands](#)." National Center on Deaf-Blindness.
- Barbara Miles and Barbara McLetchie, "[Developing Concepts with Children Who Are Deaf-Blind](#)." National Center on Deaf-Blindness.
- Anna Molinaro, et al. "Autistic-Like Features in Visually Impaired Children: A Review of Literature and Directions for Future Research." *Brain Sciences* 10, no. 8. (2020): 507. <https://doi.org/10.3390/brainsci10080507>.
- [National Center on Deaf-Blindness](#).
- Paths to Literacy. "[Robbie Blaha Discusses Calendar Systems for Children with CHARGE Syndrome](#)."
- [Sibling Support](#) Project.
- Texas Deafblind Project. "[Guidance for Planning Behavior Intervention for Children and Young Adults who are Deafblind or Have Visual and Multiple Impairments](#)."

One other resource that might be beneficial to your understanding of the impact of deafblindness on a developing child can be found at the Center on the Developing Child at Harvard University. Though children who are deafblind are not necessarily exposed to abuse or neglect, their sensory losses and the range of medical needs and interventions they experience early in life can have impact on their emotional development that is similar to the impact of abuse. Take a look at these videos and think about how they might apply to a child born with deafblindness.

[Brain Architecture](#)
[Toxic Stress](#)

CREDITS & ACKNOWLEDGMENTS



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