

THE PARENTS

+ DEAR 6M,



Thank you for choosing to run "The Parents".

Most of us spend our lives in deliberate denial of all the bad things that might happen to us. We could get ill, or someone we love might die tomorrow. Not thinking about these things is the right strategy. However, this scenario takes you to one of those "what ifs": What if my child turned out to be mentally disabled? While few imagine it will happen to them, sometimes it does - and then what?

WHAT IS THIS SCENARIO ABOUT?



There are lots of disabled people that need their story told. However, that is not the goal of this story. This scenario is about something else: It is about becoming a parent, and not getting what you expected.

Becoming the parent of a disabled child is like travelling to a different world. An inhospitable one, where nothing is what you thought it would be. This is the story of what that means - not only for you as a parent, but also in relation to the world around you, to your child and to you as someone's life partner.

This story might get dark at times. However, it might also be heartwarming and happy - that depends on what the players decide to put into it.

THE SCENARIO - AT A GLANCE

The Parents is a scenario for **3 players and 1 game master**. Two of the players will be playing the protagonists of the scenario, while the third player will be stepping in and out of roles, sometimes playing a teacher, a doctor or a family friend. The scenario takes about 30 minutes to prepare, 3 hours to run, and 30 minutes to round off. There are three different types of scenes:

- -Scenes where the parents are talking to a professional
- -Scenes that focus on the parents as a couple. These always have an outcome.
- -Narrative scenes about the child

STORY

This story is about two people who become parents for the first time. During the first couple of years of their child's life, they start to suspect that something is not as it should be. However, the professionals around their child - nursery school teachers, doctors - do not acknowledge that there is anything to worry about.

This changes when the child reaches kindergarden age. Now the parents experience being accused of bad parenting. Eventually, the child is diagnosed by a health care professional, and it turns out that the child has a severe developmental disorder.

Meanwhile, the parents are having to react to both their child's behaviour, and each other's worry for the child. This takes a toll on their relationships and carreers.

The story ends with the child turning 18.

A NOTE ON REALISM

It is up to the players to decide the specifics of the developmental disorder the child suffers from. The important thing here is that it is quite severe, and it affects the child's ability to provide for themselves in the future, as well as how the child interacts with other people. It is also not a handicap that can be cured - it is something that both the child and the parents have to learn to live with.

Since the purpose of this scenario is not to portray a certain type of disability, it is important that players give each other some leeway in terms of how the disability is portrayed. There are some general discriptions in the appendix that players might use, if they prefer. I advice not to choose something with which the players are too familiar, as it could subtract from the emotional authenticity if other players "get it wrong".

ABOUT THE AUTHOR

In 2014, I became the mother of a beautiful little girl who was later diagnosed with childhood autism.

Writing this scenario has been therapeutical for me, but I also have another agenda: That our story should be told in order to encourage a bigger understanding of what it means to parent a child with a developmental disorder. My hope is for a more understanding and compassionate world.

BEFORE THE GAME

Start by introducing the game to the players. Decide who is up for playing the parents, and who will be supporting cast. Note that the supporting cast has more reading material than the parents.

Before giving the players the characters, you should hand each of them a post it pad.



BRAINSTORM:



Post its



Pens

Ask the players to do a brainstorm on these questions. Jot down keywords on the post its, and save them for later.

- What kind of life experiences do you hope for your child to have?
- What do you hope that your child will achieve?
- What kind of relationship do you hope to have with your child when they are grown?
- Envision a scene from your child's life as a young adult or adult that you hope will come to pass.

In the appendix, there is a mind map to help players brainstorm about their hopes and dreams for their child.

MAKING THE CHILD

Before the game begins, the players have some decisions to make regarding the child. Write their decisions down on a separate post it, and leave it where everyone can see it.

Spend some time with the players sharing their dreams (from the post it brainstorm) that might apply to this child. Then decide on the questions below.



NAME?



GENDER?



DISABILITY?

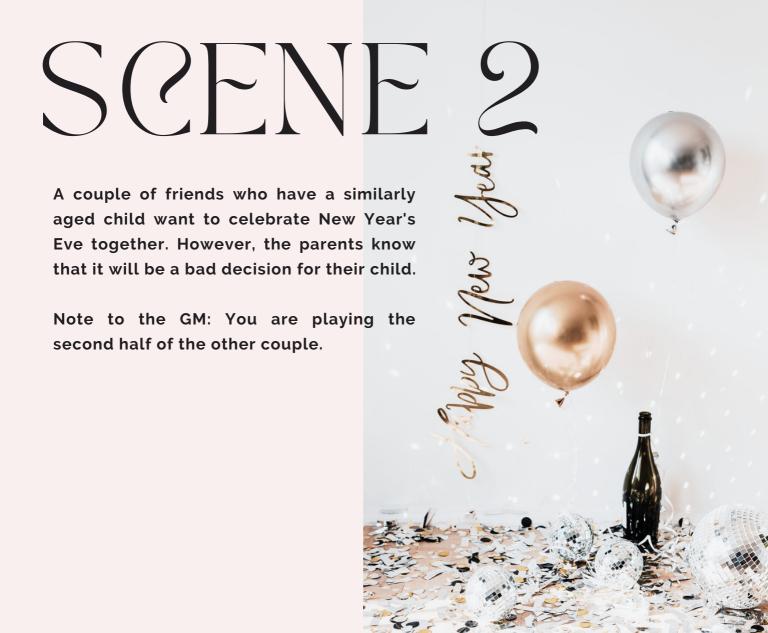


The first scene takes place in créche. The child is 1,5 years old, and has not yet started talking. The parents are beginning to worry. However, the teacher has her own agenda.

DESCRIPTION OF THE SCENE:

In this scene, the parents have been called in for a standard chat with the teacher in the crèche. They are worried about the child, but the teacher does not see any reason for taking action. Before the scene begins, instruct the parents that their goal for this scene is to either get the teacher to take action, or get proof that there is nothing to worry about. Instruct the teacher that s/he wants to come out of this talk with as little work as possible.

The scene concludes with the teacher telling the parents that they need to stimulate the child more.



DESCRIPTION OF THE SCENE:

The parents have just had a meeting at the bank, and are on their way home when they bump into another couple. They are old friends, but have not seen each other a lot lately.

The friends suggest that they celebrate new year's eve together, as they both have small kids.

It should become apparent that there is more at stake than one evening: This is about the entire friendship.

Before the scene, make the parents aware that their child responds very badly to strangers, variable bed times, loud sounds and bright flashes of light.

OUTCOME 1

The parents successfully manage to explain to the other couple that even though they will not be able to celebrate new year's eve together, they are very fond of them, and they need their help and support for whatever it is they are going through with their child. In the future, they will make more of an effort to keep them in the loop, and they will get better at suggesting ways in which they can see eachother.

The other couple become part of a support system around the family. Whenever things get hard, there is always someone to lend an ear, and who can be the parents' ambassadors to other friends. In the end, this makes them more robust as a family.

OUTCOME 2

The parents manage to set their boundaries, and explain to the other couple that what they are asking is not an option. However, in the process they also manage to push their friends away.

Ultimately, the parents fail at building a network around them. They wind up becoming more isolated, and they have little to no social life outside of their own family.

Narrative sequence:

Ask the parents to describe a scene at home which illustrates how the child shows affection.

DESCRIPTION OF THE SCENE:

Help the players get started by setting the scene: It is Sunday morning, and the parents are still in bed. You have just woken up. What happens next?

Note: It is up to the players to decide if this is a positive or a negative scene. Since only two players are involved, make sure that it is short.



The child is now 2, almost 3 years old. S/he has started in kindergarden a couple of weeks ago. The kindergarden teacher has asked them to come in for a meeting.

DESCRIPTION OF THE SCENE:

The kindergarden teacher suspects that the child is disabled. She intends to report her suspicion whether the parents approve or not. This meeting is intended as information. She stresses the importance of early intervention, and chastises the parents for having reacted too slowly.

You might continue the scene a little while after the parents have been informed, to see how they deal with the teacher's suspicion.



The parents are discussing if they should have another child. They have realised that their firstborn has some severe challenges, and it might be genetic. If so, the next child might have the same issues.

Or it might not.



DESCRIPTION OF THE SCENE:

The parents are at home. It's evening, and the child is sleeping. Give the players some time to describe what their home looks like.

Let one of them bring the issue of having another child up, and let the discussion unfold. When the parents have reached a conclusion, tell them the outcome (see description next page).

OUTCOME 1

The parents have another child, and the second child is not disabled. On the one hand, the second child brings a lot of joy. On the other hand, the parents feel guilty because this child is always living in the shadow of the disabled child, and does not get as much attention.

OUTCOME 2

The parents decide not to have another child, and they miss out on the happiness that this might have brought them. However, they are also not burdening an already strained family with more work.

Narrative sequence:

Ask the parents to describe a scene where they are proud of the child.

DESCRIPTION OF THE SCENE:

It is afternoon, and one of the parents has just picked up the child from kindergarden. The child is sitting on the floor with some toys. Describe something that happens which makes you proud of your child. It could be a thought that comes into your head, something that happened at kindergarden, or something the child does.



The child is 4 years old, and after a long waiting time to see a specialist, s/he has finally been evaluated. You are in the psycologist's office, where you will be told the results of the tests.

DESCRIPTION OF THE SCENE:

The psychologist, who is very young and straight out of college, is extremely blunt when she tells the parents about the diagnosis: The child has a severe developmental disorder. She paints a bleak picture of the child's future.

The parents realise that the child's disability is a lot more severe than they imagined. When the they get emotional, the psychologist hides behind a facade of aloof professionalism.



The child is now 5 years old. The parents have applied to a good special school, but their child did not get a place.

The mother is in favour of either home schooling, or fighting to get a place at the good school. The father thinks they need to save their strength, and accept the sub par school.



DESCRIPTION OF THE SCENE:

The parents are both at work. The mother has just talked to the school, and now she is phoning the father to tell him the bad news.

The parents need to decide whether they should fight, or accept the bad placement.

OUTCOME 1

The parents decide for the mother's solution: The child must have the best possible conditions. They decide to homeschool until a place becomes available at the good school. This takes 3 years, but the child is happy and thriving.

However, the solution has taken its toll. Let the players decide if the result of the extra strain on the parent who stayed at home results in a divorce, or sick leave and loss of carreer. Or perhaps both.

OUTCOME 2

The parents decide for the father's solution, and the child goes to the bad school. For the first few years, the child seems to be doing okay, if perhaps not well. But after a while, the child develops depression and anxiety, and is no longer able to attend school.

However, both parents are able to keep their jobs, and they stay together.

Narrative sequence:

Ask the parents to describe a scene where the child was really happy.

DESCRIPTION OF THE SCENE:

It is the child's 12th birthday, and you are all sitting together at the table.

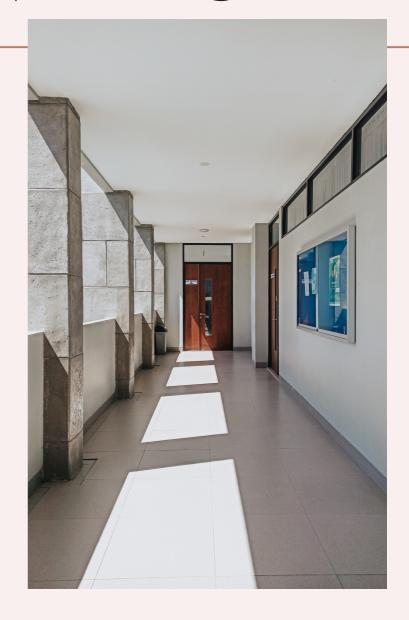
Something happens which triggers the child's happiness.

Perhaps a present, or a cake?

Describe how the child expresses happiness, and how you respond to it.



The child is now 18 years old. The parents are at a meeting with a representative from their municipality (this scene assumes that you are in a country with public health care).



DESCRIPTION OF THE SCENE:

The representative the parents are talking to explains what their options are: The parents have a choise between taking care of their adult child at home, in which case they will be self-financing, or sending the young adult to an assisted care home - in which case the municipality will take care of the expenses.

The parents know that the child prefers to stay at home for now, but they may be under financial pressure; especially if one of them lost their job in scene 8.

AFTER THE GAME

Ask the players to take out the post its they made before the game. Compare what happened during the story to the dreams and hopes they have for their own child.

How many of the dreams did not come true?

How many of them did, in spite of everything?

Ask the players to contemplate whether they think the parents should still have the child, knowning what they know now.





I used to be strong. That is how I saw myself, and how other people described me.

I used to know how to handle things. I am structured, organised. I expect things from my surroundings, and they are happy to deliver, because in turn, they always know I have their back. But then the child came.

I dreamed of becoming a parent. I wanted for the child to be my whole world, and I wanted to be theirs.

The first time I held the child was the happiest moment of my life. I was filled with the most profound feeling of love - more overpowering than anything I have ever experienced. Whenever we were apart, I imagined a golden chord reaching from my heart to their navel. As if we were attached, like in the womb.

~Continued...

But with that love came something else: Fear. Fear of failing, of letting the child down, of not getting it right. I realised that this was the one thing in life where I could not fail. I had to give it my absolute best, or I would never be able to forgive myself.

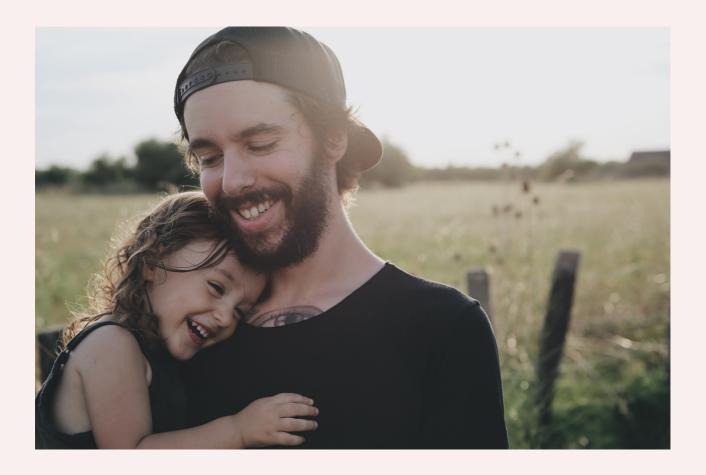
Along with the fear, the doubt and the second guessing began. In hindsight, I went too far with my organic nappies, freshly pureed vegetable dishes, etc. I needed to learn how to relax into my new role as a parent. I needed to learn to let go.

However, while I was still finding out who I was as a parent, I started noticing things. The child was not developing like they were supposed to. And yes, the books all said that every child is different, but I had a feeling - call it fear, call it intuition - that something was not right.

I mentioned it to the nurse who came round to check on us. She told me not to worry. The child was gaining weight, and had even begun sleeping through the night. "Count your blessings", she said.

I took the child to the family doctor, and again I was told not to worry. "And stop going online! It'll just make you obsess over details", he said.

I have tried to put the worry aside. But it nags at me. Nobody seems to really take me seriously. I just need someone to listen.



I wasn't sure if I wanted children. If I had wound up with someone else, I might never have had any. Or maybe I would, but I will never know, because you were sure enough for the both of us. It certainly wasn't something I needed to do, and I belive I could have lived without, and been just as happy.

I loved our lives before we had the child. Those were the best years of my life - when we were just the two of us, and we could do whatever we wanted. We went travelling, we had adventures, we met lots of interesting people. I used to play the guitar, and you could sing. We would jam together. We never do that anymore.

~Continued...

You wanted to have children, and it was part of our mutual future. Without children, there would have been no more "us". You said you wouldn't have left me, but I know the truth.

You were my fierce, strong, funny love. But then the child came, and you changed.

It was as if you were consumed by parenthood. You no longer saw me, only the child. You locked yourselves in your little world in which I had no place. I could do nothing right. I remember you correcting the way I put the baby to sleep. If babies are so brittle, how do they reach adulthood? You undermined me, and made me doubt myself as a parent.

Right from the beginning, you were always fussing over the child. But then it got worse. You got it into your head that something was wrong. You didn't listen to the doctors and nurses, no, you knew your child better than anyone else.

You are like a juggernaut. An unstoppable force of nature, fighting for your child.

But I see you at night, climbing into bed next to me. Your face sagging from fatigue.

There is nothing left for anyone else, and it's a wonder you are still standing. There are no tender kisses left for me. When I reach for you under the covers, you push me away.

You are sacrificing everything we had for the child. You are sacrificing yourself for the child.

How can I accept that?

PLAYER 3



You are the system. The community, the friends, the professionals. Everything that surrounds a family.

You are the chèche teacher who has too many children on your hands. You are the kindergarden teacher with the bleeding heart, who works overtime because someone needs to care. You are the young psychologist who doesn't get enough instructions from your seniors, because there simply isn't enough time.

You are a huge machinery that labels children and puts them into boxes, and you are broken.

But behind it all, you are also the good intentions. If you had the time and the ressources, you could be the soft hands that catch the weakest. There is so much potential, and each cog in your system would be happier, because everyone wants to do their job well.

PLAYER 3

~Continued...

But something you have working against you is lack of understanding. You simply don't know what it's like to parent a disabled child, because no-one has told you. People only talk about how things go right for them. They don't like to show their weaknesess, and for that reason, it is hard to imagine what they are going through.

In this scenario, you are going to be putting a young family through the wringer. But don't worry: They might still come out on top. Perhaps it is in adversity that we find our true strenght.

That - or we break.

In this scenario, you are the adversity.





Discriptions of diagnoses

RETT SYNDROME

Rett Syndrome, abbreviated as RTT, is a rare neurologic developmental disorder, which is most commonly seen in girls. It results in both mental and physical developmental defects. It is most likely caused by a mutation in certain genes, and is not usually present in the parents' genetic makeup.

Children with RTT appear to develop normally for the first 6 months - 1 1/2 years, though they may seem on the quiet side.

After this, they begin to unlearn things that they were previously capable of, such as language and fine motor skills, and there is a general gradual deterioration. The child seems to withdraw from the parents, and has frequent meltdowns similar to children with autism. Early intervention is important at this point, as the appropriate training programme can help the child, although they will never achieve a normal level of functioning, and are not likely to develop speech.

Other health issues might develop over time, ranging from chronic constipation to epilepsy and problems breathing.

If the child has atypical RTT, the disorder might be less severe. The players should agree on the severity of the disability before the scenario begins.



Discriptions of diagnoses

CEREBRAL PALSY

Cerebral Palsy occurs through damage to the brain, often sustained during pregnancy or birth. It can vary widely, from light involuntary movements to severe disability.

An infant with severe CP will appear either too slack or too stiff. As the child ages, the stiff muscles become too short, and the child is not able to control them properly. The joints may also become affected, so that the child is not able to stretch out bodyparts such as hands and feet. Early intervention is crucial so the child can receive the right therapy.

Most children with CP also develop cognitive problems and problems with language acquisition, but only the few are so severely affected that they appear retarded and never learn to speak. The majority also learn to walk, although perhaps not to the degree of normal function. Many also have ADHD.

There are three forms of CP: The most common involves spastic lameness, whereas the two other forms also involve involuntary movements.

Before the scenario, the players should decide on the severity of the disability.



Discriptions of diagnoses

AUTISM SPECTRUM DISORDER

Autism Spectrum Disorder (ASD) is an extremely broad diagnosis, which may range from issues with social interaction to severe cognitive problems and inability to communicate. Almost all children diagnosed with autism have issues with "theory of mind", which is the ability to perceive a situation from another person's perspective. Also not uncommon in autistic children are physical problems such as coordination, constipation, ADHD, epilepsy, anxiety and sensory problems.

While some children with ASD suffer from low IQ, others are highly intelligent.

Autism in children can be difficult to diagnose, as the child seems to be developing normally for the first few years. However, there are three symptoms which may be more or less predominant:

- Impaired ability to interact and connect with other people particularly other children.
- Communicative issues, such as problems acquiring verbal language, or with understanding non-verbal language.
- Stereotypical activities and movements. This may be anything from unusual obsessions to repetitive movement, such as finger flicking, rocking or jumping up and down.

Players should decide on the severity of the diagnosis.

