

The Package

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1 The Package - What is inside?

I took the title of my project from my uncle. He said at the 30th birthday of my cousin, that “When I took home for the first time that little package, I knew, that from now on, everything will be different.”

What is a package? Something wrapped up in paper, or in clothes. Something, which, is hiding something inside. Something, what you are waiting for, something which is still a surprise. Something, what you just imagined, what is still just living in your fantasy.

You are a package. A package of bones, skin, flesh, blood, genes. That package of blood, flesh and genes is known by the others being „you“. Do you know what is inside really? Do you know how this packages future will be? Would you like to know? Would you decide to go under medical tests to discover how many minutes, days, years left to this package?

Would you be able to decide about the future of another package? Would you sort out a package, if it would contain some chromosome disorder? Would you take home a package which is sorted out by someone? Do you believe in the pack of tools of Science? Do you think that Art could help? Do you believe that owning an Art piece is a privilege?

The project titled „The Package“ would like to speak about responsibility, ethic, beauty, belief, future, life, art and science, by showing some statues of possibly living, once lived and with the help of science will live, creatures.

2 Customer

I don't remember to the system change in Hungary in 1989. Although, I have memories from that time. Most of my friends of my age have memories about how the Sunday ice-cream bought by the grandfather becomes less, because the price gets more. I remember however, when more and more products started to appear in little shops. I remember that housewife started to choose in between the sausages which were having a “clown face painted on” and the

normal one. I remember when the first shopping centers were opened. There were sales, special opening prices, special offers. Some people went crazy about shopping. My favorite kind of sale was the “five minute” sale. The system was that a nice honey voiced lady, employee of the supermarket, picked one product, and said through a microphone that this product has less-price for five minutes. This caused great runs for the customers. Great fights also sometimes. It wasn’t easy to get to the bakery side from the pet food. Most of the time the product on sales was something, that you might really need (like bread). Than something which you might never thought of buying (like sunglasses wiper clothes), than again something useful and so on. There was just X amount of the product on sales. It kept the customers in a predatory and winner mood. (I myself captured once two nice sleeping bags.) Than these sales were were off. There came the special offers of spring and summer and this week etc.

After buying what is new, and what “we can”, Hungarian customers studied that most of the products are going to be there in the shops, so they can buy it when they wish to. Life started to be normal. Customers realized what they want, what they need, what they wish to have. Products started to be examined by its quality (again). The price made sometimes the quality. You wouldn’t give too much money for rubber slippers, but if the same slippers would coast too less, you would think that they might have a rather bad quality.

I remember how me, as a child learned about church-ales, summer festivals and markets. I still remember the songs, sound and smell which are connected with the memory of the colorful mess of people and plastic goods and chattels. Disappointment is also connected in my mind with these events. I learned fast, that no treasures were waiting for me in those markets. The colors, and the amount of goods were promising, but the goods itself, the lack of quality and usefulness was rather disappointing. (I remember still, that the dolls heels were nearly see through and they could get easily holed there because the plastic was too thin at that part of the dolls.)

People learned about goods, and they started to choose again. Choose what they liked. What was fashionable, what was comfortable, what was “in a good price”, and never the less what the other people already had (or what they didn’t and with that you could outstand).

I have to make a comment here. Of course people from the different level of the society, acts in different ways with the choosing and buying. For high level society people a unique, high quality product is more interesting, than something really colorful “everywhere you can buy” thing. In the contrary, for those people whom are manage a

household from less-amount, the price and the shine is more important.

I don't want to go into details about shopping habits. At the end the people are acting the same. They are choosing those things for themselves for their household, for their flat, which by their thoughts, is the best for them. The act is the same when someone is buying the one and only, unique painting, or a little blue glass cup (made in China), fitting in the blue glass collection. Choosing the one, which is fitting. Choosing the one, which fits to ones thoughts, or at least it fits more than the others. Choosing something, which fits to one's imagination.

The plastic slippers are not so nice...Sometimes they are, but with me, if I can be honest, never happened that I bought plastic slippers because of their beauty. When I happened to buy a pair of those, I always had to. After finding the slippers section of a shop, than try on some, than decide next to the least colorful and cheap, I bought those. Than I had slippers and those slippers were mine! When I went to the swimming-pool, and took those down from my feet next to the other nearly the same plastic slippers, it was obvious that none of the others could even be mine. And when sometimes happened that I had the same kind of slippers like someone else, It could cause a little mix up like: "which one is mine, really?", it could also cause to make new short friendships "look, we have the same", and sometimes it could cause jealousy like once when I had the same like my boss had(she was jealous). So I, as an owner, not just had some slippers, but as an owner I already had some (rather practical and reasonable) relationship whit those slippers too. (And through those slippers some strange relationship to other people, and their slippers..)

Because of a must I bought slippers. Then I accepted them, I called them mine. I started to count on and with those slippers. From the no knowledge of those special slippers even existing, I got to the point to adopt them.

Or is it possible to call it adoption, if those are only slippers? Isn't it the same procedure when someone decides to have a dog, or a cat? One have an idea, a feeling," a must" that he or she needs, or wants an animal. Than he or she decides about it's how about. Get one from an animal home, or from a breeder. Get an older dog or a puppy. Or just happen to see a nice kitten puppy at a friend's house, than his or her feeling gets growing.

When one decides to buy, or have a new thing for himself, I think I can call it adoption. When, during, for example, hiking he imagines him wearing a new, cool backpack, he adopts that idea, than maybe, for the next hiking he buys that backpack. The backpack becomes a part of the picture of his own picture of himself.

3 Adoption

Although, I write adoption is every act, when one is trying to complete his imagination, adopt a child is much more difficult, than adopt anything else in many layers.

Adoption could be cure for childless parents, and for unwanted, but born children. Adoption seems to be good for each party. It is good for the child, because he is going to grow up in a family. It is good for the adoptive people, because than they are going to be parents. It is good for the country, because than the costs of the child are not charged to it. It could also be good for the blood mother, sith she doesn't have to feel bad for her child.

The only problem is that the child is not the same as plastic slippers. One may wish to have a pair which fit to her ideas, but it may not become real.

Adoption is the end of a long road. Sometimes tragedy and sad stories are beforehand. From the point to realize that something is not right with the couple, through the long and painful surgical interventions to the certainty of infertility. The couple has hard time to keep on holding each other, not to blame each other for the failure. The road continues with endless procedures of the bureaucracy with the hope that at the end a child is going to be a new part of the family.

An own, blood related child, without being biased against the child, is the best, the most perfect one from all of the children. Somehow human thinks, that what is he, it is, in the most circumstances, the best. So if I want to have a child, he or she should be like me, so than he or she is going to be the best. If he or she is mine, he or she is better than the others. If he or she is mine I want to protect him or her, use him or her, keep him or her as I wish to. Disappointment comes when the child is not acting how his parents want him to do. Disappointment could come again, when the parents relationship starts to break apart. In this cases when one of the parents gets angry to the child, it is often said; "you are acting like your father". It is when the parents are afraid to feel the same disappointment about the child, like they felt about each other.

What is happening when the child is an adopted child, and his blood parents aren't known by the adoptive parents? It is much harder to be patient, to be satisfied with the child.

For a blood parent it is not an easy decision to surrender of the child. Even if the family is living in rather hard circumstances, deciding

about a little living relative to be unwanted is emotionally quite a challenge.

Inasmuch as I'm not a parent, these are my collected thoughts about the adoption, and I guess it is much more colorful, than I can even imagine. What I could find out about adoption, it is the procedure how it goes and what its need from the adoptive parents. I found out that sometimes adopt a child from abroad is much easy, than try to adopt it from the country of the adoptive parents. The adoption procedure could take ages and when the parents are not even thinking about it, child is coming. In Hungary to adopt a child it is the best if you are living in a long term relationship (marriage), you are under 30 years old and you have a good economic circumstance. The child, whom you want to adopt must be the youngest of the family. So for someone over 30 years, alone it is rather hard to have a child adopted. If someone is married, living in a relationship over 30 and has a family with a little kid, she can't adopt a little bigger other child. If one says that a gipsy baby is also good for her as child to adopt it is more possible to have a child sooner than if she would have said that just a white baby could come.

These parameters are narrowing down the possibility to adopt. Also showing some not so ethical rules and discrimination which is performed by the country against orphans in the early childhood.

Although the child is not let to be mixed up in a family, which is not a real family, the couple are not married, or it is not even a family, since it is only contains one person the country doesn't provide him nice, warm family home.

Home is made by someone who is takes care of his environment, who cares about other people, who tries to be satisfied with himself. Let me start my chain of thoughts about care with someone who is making a new home with furnishing a comfortable nest.

Journal Entry—Decree of Adoption
BY HUSBAND AND WIFE
Gen'l Code, Secs. 8029.

Probate Court, Franklin County, Ohio.

IN THE MATTER OF THE ADOPTION OF } March 26th 19 25
Marie Anderson } **DECREE**

This day being the day appointed, the Court proceeded to a full hearing of the petition filed in this case, and the examination of the parties in interest, under oath, and finds therefrom that the petitioners are husband and wife; that they were married on the 19 day of June 19 07, at Columbus, O.

that Harry H. Long the husband is of the age of 39 years; that Lura Long, the wife, is of the age of 39 years, and that the place of residence of both is 295 Stewart Ave. Columbus, Ohio

The Court further finds that said child Marie Anderson sought to be adopted is 4 years of age, was born on the 22nd day of May 19 20, at - and her place of residence is 295 Stewart Ave. Col. O.; that said child is 'not possessed of any property—

The Child Welfare Act
ADOPTION ORDER

In the County of Durham Judicial Court of the District of Durham
 HIS HONOUR JUDGE }
J. P. Kelly } Monday, the 29th
 IN CHAMBERS } day of November, 19 76
 In the matter of James Allan Mullett

resident in the Province of Ontario and born or alleged to be born in the Borough of Scarborough in the Municipality of Metropolitan Toronto in the Province of Ontario, on the 29th day of January, 1976, as appears by the Registration Number ██████████ on the certificate of birth registration issued by Province of Ontario

AND IN THE MATTER OF *The Child Welfare Act.*
 Upon the Application of Raymond John Sabourin of the Town of Pickering Regional in the Municipality of Durham and Patricia Anne Sabourin his wife, both resident in the Province of Ontario, for an order for the adoption of the said child;

Upon Reading the recommendation of the Director (Director or local director) under the said Act and upon considering what was alleged by or on behalf of the said applicants and being satisfied that compliance has been made with the said Act:

It is Ordered:

1. That James Allan Mullett be and is hereby adopted as the child of Raymond John Sabourin and Patricia Anne Sabourin
2. That the name of the child shall be Sean Michael Sabourin

Entered: Dec 1/76
 20-00-028 (8/75) *lub* *J. P. Kelly* (Judge)

When someone is furnishing his flat, it is done by the thought that it has to be a comfortable nest. It has to be furnished with “adopted” things. Things what he likes for some reason. An arm chair, which is comfortable to watch football from, because he is a football fan. A coffee table inherited by his mom, that one reminds him to his childhood. etc. Sometimes art works becoming a part of a comfortable home. Although the home decorated art works are not usually coming from museums, during huge exhibitions the museum shops are offering nice reproductions from the actual exhibited artist. After the exhibition and before well-deserved coffee, during examining the special offers of the museum shop, the visitors are chatting about Art, or an art work - feeling it appropriate. Sometimes I catch sentences, like “I really like this picture, but I wouldn’t take it into my living room”. Although the same couple would buy the garden gnomes in a gardening market for refreshing their little garden, or angels for the Christmas decoration, or Christmas elf. During buying those goods you wouldn’t think that you wouldn’t take it into your living room. I’m not speaking about not wanting a garden gnome into the living room, because it should be in the garden. One would think about its cuteness, not its “gnomeness”. One would think about where he would take it in his garden. The same would happen with the Christmas elf, one would think about that the elf with the blue socks, or the elf-girl with the red sock would fit more to his Christmas decoration. He would not think that they are ugly, or maybe, he would think that they are, but this is just because he would find them kitschy. Most possibly one wouldn’t think about those creatures gnome, “not normal” form. Of course he wouldn’t, sith the elf should look like an elf, the garden gnome, like a garden gnome. One would think about that how nice little legs it have, he wouldn’t try to figure out how hard it must be to jump up on the bus every day with those legs, as he wouldn’t think about which kind of dwarfism the garden gnome might has. He accepts the garden gnome how it is, and he wouldn’t feel to be bothered by indifferent, strange questions and quotes like art pieces often does. Sometimes art is more disturbing than gnomes. In an exhibition nudity could cause more waves of horror from the visitors than a garden gnome.

4.1 Confused

The cause, what makes one confused in an art gallery staffed with pictures about naked bodies and thinking about a garden gnome as a real dwarf, somehow has the same roots. It can be surprising, it is also a little bit strange to see unknown bodies uncovered. It can give

him the feeling of “I have nothing to do with it”. It is too private, too personal. Something, which is rather interesting to watch by outsider point of view, but which, is better not to try to deal with. Something, which could have been handled by him, if he would anything to do with it, he could deal with it, but since he doesn’t have to, it is better not to even notice it.

It would be something, which is strange. Not normal.

Dear reader, can you remember to your class in elementary school? Can you recall how all the children were selected by their classmates and named by some kind of a feature? No one was extreme outstanding, still nearly everyone had a nickname. The feature could be that someone was a little bit too tall, or shorter than the others, or had red hair, or had braces, or didn’t have braces...If not by the body features kids could have find some other attribution among themselves; being good at math, having problems with reading, being silent, being intensive in communication. Children are giving name to that feature which is strange for them. Children are not afraid to gaze people, if they find them interesting. The grownups in the contrary, try to pretend not seeing the strange things, try to act normal and try to teach their children to do the same. Grownups are watching what is for watch; shop windows, museums, theatre, movies.

When I observe a situation on train, bus, or tram, like an old lady, a lady with baby, or someone with a wheel-chair gets on, I often see that people react in two different ways. One is “what we don’t see won’t bother us”. The other is “what is around us, it is our business”. The person who acts like the type one, seeing a wheel chaired person, or a young mother with a baby getting on to the train, acts if nothing has happened. Looking through the window, not letting any notice about the other who might in need of some help. The person who acts in the second kind of way in the contrary; tries to speak up for the someone, whom, in their perception, needs help; someone should give his seat, someone should help get on, or get of etc.. Or speak up for themselves, share their opinion about the situation; why did you get on this train, didn’t you see it was full? I wouldn’t carry around that little baby like that, if I were you! I think the loud attention making is also a clearing about the fact, that although she has nothing to do with it, she is still someone who is helping, but again there are clear lines in between her and the person, who is in need of help.

Of course there is a third type of person, as I studied it this is a rare type, who is helping without letting everyone noticing it.

(The same situation is rather different, if it is happening in the countryside. There the people are more free and more brave to look around, my example was meant to be in a city.)

So, it is better no to try to deal with something what is not your business. If it is about disability, than you surely don't have to deal with it, sith there are official institutes which are there for them. You are sure about yourself, you won't ever get in to a situation when you have to deal with someone disabled, or just simply "not normal".

Saying this is an easy escape. "You could be more sensitive, you would have more empathy, if you should have." But of course you would never get in a situation like that, because you live your decent life, how you have to. Even if something would happen, to you or to your family or your baby there is still Science to help!

I didn't forget my words! This whole speaking about who reacts how comes from how people sometimes react to Art. I'm going to come back to this, but before I have to say some words about Science.

I believe in science. I believe in the evolution of science. I don't believe the almightiness of science. I don't believe the inhumanity of science.

5 "A doctor a day keeps the jim-jams away"

(Aldous Huxley: Brave New World)

Speaking of science it is often like you were speaking about a rather good mechanic mixed with a kind of god itself. Speaking about medical science it is more and more like that. Of course most of the people believe that they are healthy. They don't need any medical care.

When you decide to step on the way of being a parent, you would think, probably, that you, your body is ready for that challenge. More that the body, you would think that, being in the right age, having the right partner, being in the right economic situation is enough for having a child. It seems to be obvious also, that babies are born after planning, waiting-and they are most of the time really wanted by their parents.

In any case, when something is not right, you could call the (genial) medical doctor, who knew(like a good mechanic), where and what he should oil, which screw should be tighten more-than it is done, you are ready to have the child of your dreams! Yes, sometimes there are

bigger problems, than oiling, but than a little cut here and there, than you are done. Also you are in safe hands during your pregnancy (or your partner is in safe hands during her pregnancy), because the safeness of the baby and the mother is guaranteed by the doctors. There would be some tests which would tell about you and your baby condition. There would be some tests which from some samples of your spit would tell you that everything is fine. Not even a needle would be needed for this procedure.

If it would be so, than there would be no need for institutes for people with disabilities or institutes for orphanages.

This is what is known about medical science by most of people. Or this is what people wish to be, so we believe, what we were told to. These beliefs are thought us by the media around us. But you have to be honest it is rather good to believe, even if you have your personal experience by healthcare. You experienced, that your heavy headache couldn't be cured, because your doctor has no idea what's it is caused by. Your recently occurring stomach ache must be there because of your depression...And even if your doctor knows what is wrong, sometimes the well known cure dosen't have any effect on you...

I may sounded sarcastic, it wasn't my attention. What I wanted to illustrate, maybe in a harsh way, that medical doctors are, of course, humans. Some of them have bigger talent than the others, sometimes they are more lucky than their other collages, but still their knowledge is finitesimal. Their responsibility is huge.

When you think about science, and in this case about having a baby, you are often forget about two things; the unknown, and the accident.

The *accident* is meaning different things in this case. First, that not every baby is a planned child. Not every "not planned baby" gets discovered before the 11th weeks. In the contrary not every planned and discovered in time baby is surely delivered to the point of the safely birth. There are some medical care routines, which have the possibility to discover if there is something wrong, but some of the tests have the danger of hurting the mother or the child. Medical malpractice can be caused during the birth giving too. Also sometimes a not noticed fact, like a tangled cord could cause the danger and the damage.

The *unknown* is something, what you and your doctors won't count in, because you have no knowledge about it. This unknown thing is often hiding in your genetic map, or in your family's genetics.

Rare times your genetics don't show to you, but you have a possibility to perpetuates some genetic differences or diseases. I'm thinking about those cases when a white mother and father giving birth to a black child, or a couple of black parents are having a white

child.(Of course I'm speaking about those cases when no cheating, and no white, or black milkman is involved in the story...)

Like in the case of Ben and Angela Ihegboro, a nice black couple, who are having their second daughter, who is happened to be a nice white child, with blond hair and blue eyes and who is not an albino baby.

Rare time diseases also can hide from doctors. If one has no knowledge about having an ancestor, who had dwarf syndrome and the fetus doesn't show any sign of dwarfism in dimensions, the baby can born also with the right weight and size, but later on he stops growing than the parents has to deal with that child.

Naturally other (can I say more delightful? surely not..), genetic disorders are existing, like having susceptibility of becoming deaf, or blind.

There are facts which are hidden, not known, so no one could count on them. Not even rather prepared doctors. (In my opinion no one has the right to blame a medical doctor just to being a medical doctor, not to see the future and the past, and being able to tell you what is going to happen...)

The living environment and circumstances could also influence the growth of a fetus. Infected water, vitamin A deficiency, not enough food, hard work, medicine intolerance could make dramatic changes in the fetus development.

5.1 "Didn't you get tested?"

What is happening, when the setup is working? When the doctor is telling you about your fetus, that it has a down syndrome? Or your fetus is going to be a dwarf? Or your twin girls are attached to each other by their belly? What do these worlds telling you?

„Let me get rid of the elephant in the room by disclosing that, yes, I did make a choice. Although I was 38 at the time of my pregnancy, my husband and I decided not to have an amniocentesis. We didn't opt out because of religious or political beliefs. I believe strongly in reproductive freedom, and I would never presume to tell another woman not to get tested or not to abort an unwanted pregnancy. But we wanted this child, and we didn't think the results of a genetic test would change our minds. We don't believe prenatal testing can tell you all there is to know about the person your child will become, nor can it predict the future happiness of your family.”

Here is a quote from a paper by Rachel Adams, which I think nicely says what I would like to write about. Would a genetic test say about

your future? I mean yes, some of it yes. It says that if you are going to decide to have a child with a disorder you might have to work more, or work maybe in another way than a parent of a healthy child. But does the genetic tests saying that without that child you are going to be happy? Is it like that so, that knowing something about your genetic map gives an easy answer and an easy choice to you? Would a healthy newborn baby promises a whole life of peace and happiness?

5.2 History



I studied that humanity try to select those kids whom are not strong, good, healthy enough. From the ancient Greeks it was possible to get rid of the child who was not wanted by the family. (Although there is

a well known legend about the ancient Greeks and their procedure at the Mountain Taygetos of killing the not healthy babies, it is not quite true. The babies were not killed, but have been taken out to a well known place, from where people who couldn't have babies could have taken them home. It was the place where slave traders and brothel house owners were regularly there to collect the taken out babies, than brought them up for themselves.)

“In the Roman Empire however, the disabled seem to have faced a lot less discrimination. Obviously, Romans were not prone to look at their imperfections in a manner of disgrace or shame but rather even use them willingly as an additional, descriptive name. In the European middle ages, the majority of disabled people had a hard stand in society but

still depended on social support. Those who could not work as a jester or were exhibited on fairs had their place in society as beggars which enabled at least part of them to make a living. Every handicap was thought to be self-inflicted and was therefore blamed on the disabled whose “worth” as a human being was clearly diminished, not least because the physical condition of men was believed to reflect the character of their souls. Consequently, disability was seen as manifestation of sins. Some disorders were even regarded as a satanic creation which led to abandoning, torture and murder.

At the edge to modern age, treatment of disabled changed slowly from torturing and mocking them to locking them up in madhouses and separating them from society.

In the sixteenth century, especially mentally disabled people first became subject of medical research but it was not before the middle of the nineteenth century, that “madness” started to

be perceived as an illness. However, the late nineteenth century was the era of freak shows and display of all kinds of physically abnormal humans. Around 1840, P.T. Barnum began to exhibit disabled persons for entertainment.

At the end of the nineteenth and beginning of the twentieth century, the school of eugenics which separated society into valuable and inferior individuals arose in Europe. Eugenics aimed at genetically improving mankind by promoting or excluding the respective parts of society in

terms of contribution to the gene pool. In Germany, these beliefs culminated in the so-called racial hygiene of the Arian people. This meant “freeing” the German pedigree from influences by presumed inferior (physically or mentally handicapped) and foreign individuals, first by

prohibition of “mixed” marriages and routinely executed forced sterilizations, later by explicit mass murder.



With the beginning of World War II, the National Socialist regime started killing children and adults which they considered unworthy. Those were first children with any kind of malformation; later inhabitants of asylums and nursing homes were eliminated in masses. Doctors and nurses were obliged to report every case of a physically or mentally disordered child to the authorities, so that they could be sent to special facilities - nothing less than killing centers. At least 30 of those facilities, officially dedicated to euthanasia, existed in the German Empire. There, children would either be used as subjects for medical experiments or intoxicated slowly until they would eventually die from an infectious disease. Not only should eliminating the unhealthy and abnormal serve the purpose of opposing the loss of healthy young men dying in battle to prevent a “weakening” of the German race, but also, it was considered getting rid of ballast in order to save resources in form of hospital beds, medical personal, food, drugs, etc. which could instead

be used for warfare. Abandoning and even killing of disabled humans, may it be newborns, children, or adults can be found from ancient Greece to the middle ages and to modern times. Fear and loathing towards the uncommon have made their way through the ages. Still, the notion of disability is a social construct rather than an absolute definition since not the impairment itself but the consequences for a person are decisive for categorization. A handicap is always the combination of a deviation from the norm together with a negative social reaction to it. Social reaction and valuation of course, can be most differentiated in different cultural perspectives and thought styles.”

Later in the history of humanity there have been pogroms against selected section of the society, not necessarily against disability, it was simply enough to have(or want) an other kind of religion, have another kind of color of skin, or simply have been coming from another country. This positive habit of mankind didn't change a lot stepping into the nice and glorious 20th. century. People got to learn a lot from the I. and especially from the II. World War. Learn about humanity, and the outrage against humanity.

I think, we think that now, in the 21th century, people act rather differently. And it must be true in lots of ways. There are schools with a curriculum which accepts different children and try to give for all pupils the same kind of education. There are international programs which are dealing with migration, with different cultural background people, with disadvantaged children. It is surely true, that there are lots of trying efforts to make our world a better, or more receptive place.

Still, sometimes I feel, that these efforts to give the same education for different students, to found schools for migrant people, that all these efforts are making the gap more deep in between the “normal” people, and between those whom are offered to be helped.

Once I mentioned it to a friend of mine, who is an educator in a craftsman manufacture employees Down-syndrome people. To my concerns she reacted in this way: “Do you also feel weird when you meet Down- syndrome people? Have you ever met one before, I mean one at a time?-I answered no.-You see, you can meet them on streets, in parks, but they are always a group of people, not entire persons. They are taken in work places for mentally retarded people, for schools just for them, than they are always moved like a group. This might be the cause to feel strange being among them. “I had to say that it must be true. If society separates people, than you can meet those people in special places (like in a human zoo), the experience is to be in a not ordinary, special event. The work places for peoples whom are needed special care is a good development, the

disadvantage is that those are work places for people who are needed special care. I believe that the society opens with time and there could be more social connection in between the “normal” and the “not ordinary” people.

5.3 “Bringing home Holland”

During my research I find some blogs written by families of children with some kind of special care. The blogs are reporting about how their kids are dealing with their not ordinariness, but mostly about an everyday family life. One of my favorites called: “bringing home Holland”. The story of the “Holland family” starts here:

“Everyone was so excited for little B to get here but things just felt off. I had an overwhelming feeling that something wasn't right, although I thought he would be stillborn. My fabulous Dr did 3x weekly BPP just to keep tabs on everything. On Aug 2 he also did an ultrasound. The wonderful US tech said that his limbs were showing 6 weeks short and his head was 2 weeks oversized. As a nurse I knew that those were signs of dwarfism. Due to the decreasing BPP they decided to deliver him that day. I had 5 hours to deal with the news before he was born. I was crying and distraught to say the least. My 6'3" husband simply said we will deal with whatever comes, we can't change this and he is our son. What a man, it brings tears to my eyes to think about it even now. Our little guy looked so perfect when he was born. I had only know of achondroplasia type dwarfism - later I would find out there were over 350 different types.”

And follows like this:

“Little B was never really on the growth charts, and steadily fell below any curve. I finally contacted the LPA (little People of America) when he was about 2 months old. They were wonderful and sent me the following poem in the packet.

WELCOME TO HOLLAND

by Emily Perl Kingsley.

I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guidebooks and make

your wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!" you say. "What do you mean, Holland?" I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy.

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to some horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy a new guidebook. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life you will say, "Yes, that's where I was supposed to go. That's what I had planned."

The pain of that will never, ever, go away, because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland."

When I read the poem first, I was amazed. It was simply a too simple way to describe how a parent of a child with a disorder would feel. I was expecting ways of shocks, lists of extra costs, stories and advises for the life what follows with that child. Instead of all these, I found out, that "life goes on", you just have to accept some other circumstances, than what you would have been imagined, what you would have been waiting for.

After I found that story, I told it to some friends of mine. I always got the answer, it is a sweet comparison, but raising a disabled child must be much harder than this. The other comment was to this story that,

“yes, maybe with a dwarf, or with a Down-syndrome baby it is like that, but”...But what? The majority of the society has no idea how it feels to raise a handicapped child, but when there is a description written by people whom are actually dealing with this question in their every day, it is said to be not true? Whom would we believe then?

5.4 Kept alive

“Then "My Ford," she wondered, "have I given this one its sleeping sickness injection, or haven't I?" She simply couldn't remember. In the end, she decided not to run the risk of letting it have a second dose, and moved down the line to the next bottle.

Twenty-two years, eight months, and four days from that moment, a promising young Alpha-Minus administrator at Mwanza-Mwanza was to die of trypanosomiasis the first case for over half a century. Sighing, Lenina went on with her work.”

The growth of knowledge of science shows itself in the knowledge of keeping someone alive. Being alive in this case doesn't necessarily meaning someone who, after kept alive, is being a good talking company. Or not one is going to be a good striker in football or in any sport. It could mean one is living in a vegetative state. Sometimes one, who lives bedridden. The main body organs are functioning, air swept in and out from the lungs, heart is beating blood is circulating. The organs may need some mechanic help. The communication with the patient may be uneasy, or there may be no communication possible, but still the body is kept alive.

The media reports about more and more cases of babies with strange diseases kept alive. Miracle like the little ones still living. Rather special cases they are surviving and start to grow up. I could be that it is just an influence of the media, what is felt by its presence in our everyday. I don't thing every special case could get hype by the news. If those babies whom are known by their poor condition are growing up, after a while our society would face a lot more disability, than it does now. It is an omen which pictures a science fiction like world in the future. The idea comes from the increasing lifetime, the increasing quality level of life and the more and more pollution of earth. (Like in a good, old science fiction movie.) A little bit weak, but otherwise healthy babies have been staying alive, growing up, than having children again-maybe giving through the weakness in a harder level. (This is one of the reasons why there are so many people have allergic for so many things, as a doctor said to me.)

6 A diverse range of human activities

“Art is a diverse range of human activities and the products of those activities; this article focuses primarily on the visual arts, which includes the creation of images or objects in fields including painting, sculpture, printmaking, photography, and other visual media. Architecture is often included as one of the visual arts; however, like the decorative arts, it involves the creation of objects where the practical considerations of use are essential—in a way that they are usually not for a painting, for example. Music, theatre, film, dance, and other performing arts, as well as literature, and other media such as interactive media are included in a broader definition of art or the arts.[1] Until the 17th century, art referred to any skill or mastery and was not differentiated from crafts or sciences, but in modern usage the fine arts, where aesthetic considerations are paramount, are distinguished from acquired skills in general, and the decorative or applied arts.

Art has been characterized in terms of mimesis, expression, communication of emotion, or other values. During the Romantic period, art came to be seen as "a special faculty of the human mind to be classified with religion and science". Though the definition of what constitutes art is disputed and has changed over time, general descriptions mention an idea of human agency[6] and creation through imaginative or technical skill.”

6.1 Art – preconception



By lot of people Art means two things; one is a quality craftsman, the other is the decorator. (For a lot of people these two meaning is the one and the same.) If you are an artist, than you must have a lot of knowledge how to make a nice a fruit composition or a bouquet for the Sunday lunch table. If you are an artist you must know about the fashionable colors of the Easter decoration. If you are an artist you must have knowledge of hyper-realistic drawing and statues in a surprising size; in rather small, or in really huge. If something is colorful, it must be art. If something contains blood, nudity and slight erotic, now that must be really art! If something made of porcelain it could easily fit to the preconception of art, and if this thing contains dolphins, sunset and sea, golden flickers, and fat cupids.. now, that would reach the point to be that much, that even I would say that is

Art, otherwise I would just say that it is a kitsch. Lots of people say about art, that it must be nice. It must be a thing which is good to look at.

It starts to be fishy, when Art is something what wants to say something. What is not nice, not rather good quality, but has a message. That kind of art can be found in museums, in galleries. That makes people bored before entering to the museums. Also this art means culture, which needs lot of money and which has no use for the people. Art sometimes means a picture, a thing which one likes, which one would like to have at home, but it is too expensive to buy.

6.2 The Fair

Although Art changed a lot since the last century, these preconceptions are still alive. There are lots of art fairs, open gallery days, free entering days of museums the fear of emotional and mental shaking stayed in mind. But what is art without visitors? Most of the art works are made to be seen. (I write “most of art works”, because I draw a lot just to myself, but maybe those drawings are not even art works because of that fact.) Art would really lose its *raison d'être*, if it couldn't get to the audience. Here is a nice example how Jasper Joffe who is a British contemporary artist and novelist given a response to the narrowing art market.

“The Free Art Fair will take place for the third and final time in London in 2009 at The Barbican Centre. This will be the biggest best most fun version ever. Artists participating were asked to incorporate the idea of free into their work by making work that they always wanted to make but felt like they couldn't.

In 2007 Jasper Joffe set up the first Free Art Fair with the participation of 25 artists all giving their art away for free in three empty shop spaces in Portman Village, near Marble Arch, London. It offered an alternative to the art market's focus on price and status. This had become alienating not just to artists but also to viewers, and art as a creative and social object was being lost. In simple terms we wanted to say art was worth more than money. The first Free Art Fair was a great success. Viewers seemed to really engage with the concept and the individual artworks, and in a wider sense it resonated with many artists, including those showing at the large commercial art fairs, who felt that the art world had been hijacked by big money. People who got art included students, homeless people, teachers, a nurse, and many people who never would have been able to become art collectors otherwise.

In 2008 (download catalogue) 50 artists gave away art work including Stella Vine, Bob & Roberta Smith, Gavin Turk, Chantal Joffe, Danny Rolph, Harry Pye and many others. People queued for three nights to become free art fair collectors, 2000 catalogues were given away, and thousands of people saw the exhibition. The giveaway was discussed as a counterpoint to the commercialisation of the art world in global publications and was featured live on all the main UK TV channels.

This year's fair will be the last in London. The Free Art Fair is made entirely without any budget with everyone giving what they love or do best for free."

If one could have an art piece at home that could open his eyes to art and could push him to be more open to art, I agree with this thought of Jasper Joffe. I also agree with the thought of the art started to narrowly speaking to people of art lovers and artists themselves. My point of view is that if the art world closes out many people from the possibility of getting in connection with art (even if it isn't meant to be like that), it chooses to lock out itself from the possibility of getting feedback, critics and maybe inspiration.

Another concern of mine about art is the belief of art should be nice. I agree with the need of switching off the outside world, and submerge in dreams and shine. I can absolutely understand the want of floating in a place which isn't existing anywhere else, and from where one could get something what couldn't get from anywhere else. I have strong feeling against the thought that this world, the world of art, is full of light, splendid, shiny pink, full of laughter. The idea of a world in black and white follows. Here are some problems (black) to be showed, but those are easily solved by the good (white). I believe the most interesting and important part of the world is hiding in the shadows, those are not easily caught on the sunlight. I believe art must speak about things, next to entertaining.

7 Ingredients

My artistic project, my diploma work was built up using these thoughts which could have been read to this point of my essay. Although these are rather different topics stitched together, my Package project is an attempt to show these thoughts in one bouquet.

8 The Package-My project

The package is a box staffed full of things. The package is pack, what you take with yourself. The package contains things which you've got from someone. The package contains memories and errors. The package contains treasures which you collected. You are a package. Sometime you may take home another little package.

8.1 You



When you look at the mirror, you see someone familiar. Sometimes the picture is surprising. You didn't noticed your face to get sunburned, or your skin become dry by the wind, your hair looks funny and those little hairs under your mouth are started to spring again. Your eyes are familiar, friendly shining. If those eyes are tired or bored you can understand them, because you feel how it is to be in the skin of the eyes body. When those eyes are flashing angrily, when that mouth become a straight line because of stress, you are there to understand yourself. Even if the reason to be angry is yourself, you can be patient, tolerant, you can wait for yourself to fill in your dreams. You can forgive for yourself.

When you start to think about procreation, you would imagine the new one like yourself. Or like your partner. Or like the best made from you and your partner. A perfect child, a reflection of yourself. A perfect child, who is going to live her life more perfect than you are doing. Who is going to avoid all the mistakes that you made.

What happens if the child is not perfect? What happens if you have to decide about your strange reflection's life? Would you feel that is all your fault? Would you think that in the eyes of the society you are not a good parent, not a good man, because your child is handicapped? Would you say simply, that my child is beautiful as it is? How would you take in the fact that your perfect grown up child chooses someone not perfect?

All these questions could be shorten down, for some (seems to be) less personal, and more general ones. Do you feel responsible to your environment? Are you a responsible person? How can you cope with

differences? How open are you? How much humanity is in you, really? How strong are you? How vulnerable are you? How much do you afraid? How much can you give from yourself? These questions, without any context, seems to be less harmful, than the questions before, although both batch of questions are asking the same. If the questions are not so personal, the task to step back and answer from an outside point of view, where the “good” answer is more visible and unequivocal. These answers could be more accepted and nicer, while maybe the answers for the first batch of question would be truer. The Package project would like to scrap the top of the mountain of these questions. My intension was to examine those questions and get closer to the answers. These are not just questions for the audience, these questions should be answered by me too. When I started a “preproject” before the diploma a professor of mine said: ”You should be careful not to play around with your visitors, they shouldn’t feel to be guinea pigs. You should take some risk yourself too.” I took his word and started to create a project next to this advice too.

8.2 The package

My idea was to create something innocent, harmless. Something which might exist, but maybe not, which can be just a figment of your imagination. Something which is loveable. Something which is not nice, but indeed an art work. Something which is one and only. Which you can adopt and take home, if you wish. Of course in the case you found to be the right adoptive parent.

The answer to the question, that what would be that thing? come easily. I decided to create a statue of a human baby. People like babies even if those are puppies of animals. A baby is helpless, needs someone to take care of him even just to stay alive. A baby has nothing to do with his parents decision, or past, he is clean and he is always the victim. He hasn’t got any knowledge about his how about. He can’t make any harm to anyone. He depends on people on the society.

Why and how would be the baby symbolize the question of responsibility? If the baby would be coming from a minority group, it could symbolize the differences. But the question would change from the general Liability and general ethic to the question of minority groups and migration. If the baby is white, the question of minority people falls out and he could be a symbol of malaise. But than what is the difference in between that baby and another baby from the shop? Why it would be a challenge to decide to take it home? It would stay within tolerance limits. I wanted to play with those a little more.

8.3 Anatomy Museum

I was, from a long time ago, interested in the different variation of twins and deformed people. First I guess, the vision struck me, but I don't remember that part. Shortly followed my main concerns; how would it be to be like them? How would it be if you have a sister always with you? How would a morning dressing up be, if it is not up to one head and one mood and idea, but two? How would it be to try to fit in a class if you would have three hands? Or just more fingers? How would it be to ride on a bus, if for someone rather normal there's always a comment from someone? I decided that the baby should have some strange deformation.

Because of my entire interest I knew a little bit about parasitic or Siamese twins, Down-syndrome, hydrocephalus, babies with more limbs or Phocomelia which means less limbs. But I took the view that I would need some professional knowledge about those syndromes. I have been in the Federal Pathologic-anatomical Museum in the Viennese Narrenturm once with my university colleagues, I knew the Narrenturm keeps interesting preparations. I asked the museum and I've got a nice answer, but at that time the museum was under a great renovation and it wasn't possible to go there and see the exhibited preparations.

I told my idea of my project and the problem, that I have no idea where I could find the needed preparations for my statues. She mentioned the Anatomy Museum of Semmelweis Medical University in Budapest. There I find what I was looking for.

The Anatomy Museum of the Semmelweis University was founded to build up a collection for helping the studies of the medical students. The museum isn't open for the public, although it is possible to ask for permission to visit the place. The First I was there with a medical student, who nicely showed me around. We were there at the time of the first examination period of the semester which is about bones. The museum was full of students murmuring the names of the parts of the bones in Latin. The whole place seems to be ancient (as I get to know it after the museum was founded more than 100 years before), the storages, shelves, some of the preparations too. In the back side of the museum a whole storage was meant to keep wet preparations of babies and fetuses with strange syndromes. At that point those little creatures didn't frighten me. I was happy to see them and the body parts of grown-up bodies were harder for me to examine them. The babies were so helpless, floating in shiny jars in yellowish liquid. They have little hairs and nails, eyelashes and they

are creased because of the liquid. I understood that they are creepy and it is a challenge to not make a freak show out of them.

As a first step I decided to examine them more. For this I decided to make some drawings and sketches of them. I thought the drawing is more personal than photographing the preparations. While photographing there is always a tool in between you and the subject. Also I thought that photographing would be too fast to understand those creatures. Drawing is slow, needs a concentrated eye and mind. Drawing also shows about your knowledge, your personality, your relationship with the subject. Also I'm more familiar with drawing.

I needed a permission for drawing and for being in the museum. It may seem to be an unimportant detail, but I had the preconception about getting the permission. I was mistaken. The Doctor who is in charges of the museum was rather open to the idea of drawing some of the preparations of the museum. He and his assistant of the museum were not just welcoming me in the museum, they were offering me free entering during the closed hours of the museum and a corner where I could "build up" my studio. The Rector too, who give me the last permission, was really nice. I find it important to write this down because I thought that if the bureaucracy health care in Hungary is so hard and slow, it must have be the same in huge university which is one of the source of the health care.

I've got the place and the permission, I've find the subjects, I was offered some professional help with the disorders, I just had to start my project. I started to draw. If I thought it is the easy way to me, I was very wrong. The first task was to choose from the collection. The museum collects well developing fetuses and fetuses with special disorders. My first drawing was made of a normal fetus in a womb. I was facing different problems. I knew how to draw fruit composition or a still life. I know how to draw a human body a nude too. The still life is easy, it is staying on its place, you can examine it closer, you can leave it there and start the drawing again on the next day. The model is always moving, needs regularly breaks, checks your drawing, says how she would like to stand. You get to know a lot about your model during drawing. Just from the little gestures, moves, facial expressions you can get some knowledge, some food for your imagination to create a bigger picture. Drawing a preparation it is somewhere in between. The subject has a humanoid form. But stands still like a statue, it is wobbling in formalin. But it isn't moving, isn't making gestures. The preparation is a dead body, which, of course I knew before. The new experience was, the attempt of having some distance in between, but not having a huge gap, which could have driven me to disinterest. Those days spent in the museum of anatomy made me understand how hard it must be as doctor to deal with a patient as a person. It is easier to say he is an object of my work, than you don't have to deal with his feelings,

circumstances, life. The doctor could just leave the patient without bad (or any kind of) feelings in that way. The drawing was hard because of the simple fact that the preparations are in jars and in liquid. If those preparations wouldn't be strange enough, the distortion by the jar would surely make them stranger. Next to these there was always the smell of the formalin, the warmth of the escaping gas and the "not of this world" aura of the place. In the first time of my life, I've got continuous nightmares every night. These were dreams, when my friends were missing parts, like head, legs, nose and they didn't realized it, they were acting as everything would be all right. Those were rather hard nights. I saw a lot of things, tried to deal with them. I was drawing and talking to the nice assistant of the museum, studying different diseases and the history of some of the preparations.





8.4 Collections

One dark winter day I started to think about not wanting to go any more to the museum. It started to be more like an exercise to me than getting closer to my diploma project. My attempt was not to exhibit my drawings, nor to make a collection, or a book about the preparations. Not to mention that those books already exist. One of the oldest books about “humanoid monsters” is the *Monstrorum Historia* by Ulisse Aldrovandi.

“Ulisse Aldrovandi (Bologna, 1522-1605) is considered the founder of modern Natural History.

Along with the collection of specimens coming from all over the world, which were one of the first wunderkammer, Aldrovandi used to collect also drawings of animals hard to find or to preserve. Thanks to artists and painters like Agostino Carracci, Teodoro Ghisi, Jacopo Ligozzi, he created a huge archive made up of 8000 sheets, from which 3000 planks are still preserved today in the Biblioteca Universitaria di Bologna.

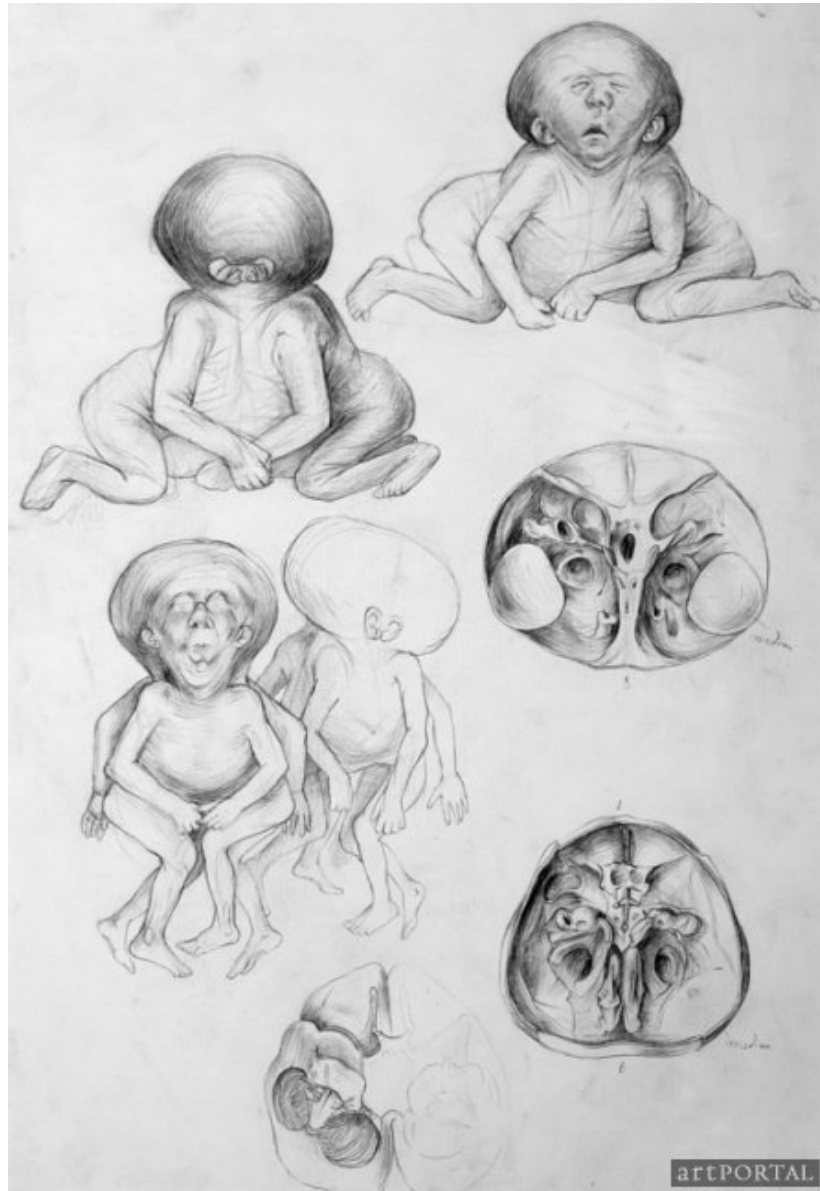
Aldrovandi published also other works like the *Herbarium*, the *Ornithologiae hoc est de avibus*, *De animalibus insectis libri septem* but the most famous is certainly the *Monstrorum historia cum Paralipomenis historiae omnium animalium*.”

The book collects monsters in a high range. Some of them might not existed before, but there are some which might existed too. Those might existed ones are distorted humans, those cases are known by recent medical scientist too.





Not just ancient books exist. There is a book about the actual collection of the Anatomy Museum. It is written by Frigyes Kőnig the professor and Rector of the Fine Art University in Hungary. *Harmonia Perturbata-Disturbed Harmony* is a book “genuine monsters” and about their “unique irregular structure” and the “logic behind the arrangement of these strange forms”. Frigyes Kőnig not just drew down the special fetuses, but wrote down their medical background too.



I realized that for my projects purpose I don't get to be depressed because of the preparations strange aura. (After this decision a friend of mine said that my hard feelings might be caused by the strong dose of formalin.) I decided to use the book of Frigyes König as a help, but otherwise I could start my experiences with the different material.

8.5 Inspiration

The reason why I took the idea of making a statue, because I felt the statues are becoming more enfolded in space. Another idea was to make some drawings about the babies. Not the drawings which were made in the museum, but an abstract of them. I didn't like this idea because it would have been much easier to me and it would have

been easier to explain as a picture of an imagination. A statue is there in the room, takes more air, one could touch it, it could fall, it could stand. Somehow it seemed to be more there (as an idea). I've got inspiration from different artists.



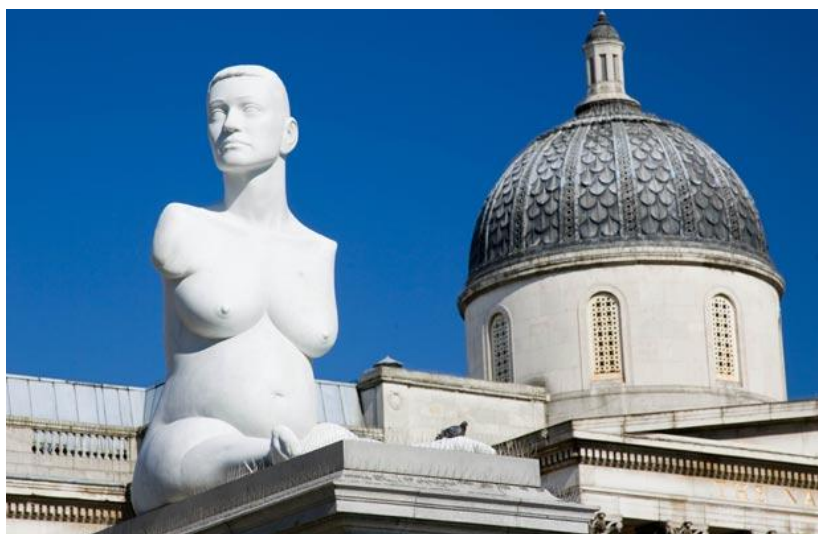
Marc Quinn and Patricia Piccinini were the two main inspiration, dough.

I get to know the Alison Lapper pregnant titled statue when it was first exhibited at the Trafalgar Square.

“Alison Lapper was born without arms and with truncated legs, a condition called phocomelia. She was institutionalized from her childhood, and is still distant from her relatives.

She posed for Marc Quinn for the sculpture Alison Lapper Pregnant. Made of Carrara marble, it shows Lapper nude and heavily pregnant. It occupied the fourth plinth in London's Trafalgar Square between September 2005 and late 2007. A large replica featured in the 2012 Summer Paralympics opening ceremony.”

The statue shows a pregnant woman sitting. She has rather short, deformed legs and no arms at all. Her face is strong, the whole statue has an effect of composition of an ancient Greek statue. A statue made of a winner from the Olympiad. Although, the body of Alison Lapper is not quite like a body of an Olympian. She is winner dough, she is going to have a baby-what else is a winning position if not this? The statue is rather close to my thinking. It speaks about the conception of beauty, about one's past, one's (and one more) future. She is beautiful, but she is someone, whom one wouldn't think to be a model of a statue. Alison Lapper wasn't the only model with disability of Quinn. He made a series of people with phosomelia.





“Quinn has made a series of marble sculptures of people either born with limbs missing or who have had them amputated. This culminated in his 15 ton marble statue of Alison Lapper, a fellow artist born with no arms and severely shortened legs, which was displayed on the fourth plinth in Trafalgar Square, London from September 2005 until October 2007. (The Fourth Plinth is used for rotating displays of sculpture.) In *Disability Studies Quarterly*, Ann Millett writes, “The work has been highly criticized for capitalizing on the shock value of disability, as well as lauded for its progressive social values. Alison Lapper Pregnant and the controversy surrounding it showcase disability issues at the forefront of current debates in contemporary art.”

Marc Quinn is a British artist who regularly works with the human body, beauty.

“Quinn’s sculpture, paintings and drawings often deal with the distanced relationship we have with our bodies, highlighting how the conflict between the ‘natural’ and ‘cultural’ has a grip on the contemporary psyche. In 1999, Quinn began a series of marble sculptures of amputees as a way of re-reading the aspirations of Greek and Roman statuary and their depictions of an idealised whole.”

Patricia Piccinini is an Australian artist who works in a variety of media, including painting, video, sound, installation, digital prints, and sculpture.

“Piccinini has an ambivalent attitude towards technology and she uses her artistic practice as a forum for discussion about how technology impacts upon life. She is keenly interested in how contemporary ideas of nature, the natural and the artificial are changing our society. Specific works have addressed concerns about biotechnology, such as gene therapy and ongoing research to map the human genome... she is also fascinated by the mechanisms of consumer culture.”



8.6 Sculpting

With these fine inspiration I started to sculpt. I'm not a sculptor, nor some one who know how sculptures are made. My knowledge from before was some experience with plasticine. I used to make some

little-little statues, creatures sometimes jewel. I have been never working in bigger scales in statues. I imagined the baby in life size, so I wanted to work at least that size.



The knowledge about sculpting was missing surely. So first I tried to make sketches and little statues about those babies whom I wanted to sculpt. For this time I realized that I can't pick one and only baby with one disease. I started to draw some of them in the way like they would be alive. I tried to imagine how they would move, what they would do.

The preparation of the statues started with the choosing those diseases which I wanted to sculpt about. My decision was made taking into account these reasons; the status has to be somehow "nice". So I sorted out all those disorders which are affecting the head, face bones, eyes. Another important point was that the disease shouldn't be something what with a little bit of surgical cosmetics it could have been repaired. The diseases had to be known little bit. I

tried to pick some, which could be found in fairy tales. These diseases reminded:

Dwarfism

“A typical defining characteristic of dwarfism is an adult height of less than 147 cm (4 ft 10 in) Since those with dwarfism have such a wide range of physical characteristics, variations in individuals are identified by diagnosing and monitoring the underlying disorders.

It should be noted that short stature can be inherited without any coexisting disease. Short stature in the absence of a medical condition is not generally considered dwarfism. For example, a short man and a short woman with average health will tend to produce children who are also short and with average health. While short parents tend to produce short children, persons with dwarfism may produce children of average height, if the cause of their dwarfism is not genetically transmissible or if the individual does not pass on the genetic variation.

Disproportionate dwarfism is characterized by one or more body parts being unusually large or small compared to the rest of the body. In achondroplasia one's trunk is usually of average size, one's limbs being proportionately shorter, one's head usually larger, and a prominent forehead. In at least one case achondroplasia resulted in a significantly smaller trunk and head. Facial features are often affected and individual body parts may have problems associated with them. Orthopedic problems can result from multiple conditions such as diastrophic dysplasia and pseudoachondroplasia.

Proportionate dwarfism is marked by body parts being proportional but smaller. Height is significantly below average and there may be long periods without any significant growth. Sexual development is often delayed or impaired into adulthood. Unlike disproportionate dwarfism, in some cases intellectual disability may be a part of proportionate dwarfism.

Physical maleffects of malformed bones vary according to the specific disease. Many involve joint pain caused by abnormal bone alignment, or from nerve compression. Early degenerative joint disease, exaggerated lordosis or scoliosis, and constriction of spinal cord or nerve roots can cause pain and disability. Reduced thoracic size can restrict lung growth and reduce pulmonary function. Some forms of dwarfism are associated with disordered function of other organs, such as the brain or liver, sometimes severely enough to be more of an impairment than the unusual bone growth.

Mental effects also vary according to the specific underlying syndrome. In most cases of skeletal dysplasia, such as achondroplasia, mental function is not impaired in any way.

However, there are syndromes which can affect the cranial structure and growth of the brain, severely impairing mental capacity. Unless the brain is directly affected by the underlying disorder, there is little to no chance of mental impairment that can be attributed to dwarfism.

The psychosocial limitations of society may be more disabling than the physical symptoms, especially in childhood and adolescence, but people with dwarfism vary greatly in the degree to which social participation and emotional health are affected.”

Sirenomelia

“Sirenomelia, alternatively known as Mermaid Syndrome, is a very rare congenital deformity in which the legs are fused together, giving them the appearance of a mermaid's tail.

This condition is found in approximately one out of every 100,000 live births (about as rare as conjoined twins) and is usually fatal within a day or two of birth because of complications associated with abnormal kidney and urinary bladder development and function. More than half the cases of sirenomelia result in stillbirth and this condition is 100 times more likely to occur in identical twins than in single births or fraternal twins. It results from a failure of normal vascular supply from the lower aorta in utero.[citation needed] Maternal diabetes has been associated with caudal regression syndrome and sirenomelia, although a few sources question this association.

VACTERL-H is an expanded form of the VACTERL association that concludes that this diagnosis is a less severe form of sirenomelia. The disorder was formerly thought to be an extreme case of caudal regression syndrome; however, it was reclassified to be considered a separate condition.”

Down syndrome

“Down syndrome (DS) or Down's syndrome, also known as trisomy 21, is a genetic disorder caused by the presence of all or part of a third copy of chromosome 21. Down syndrome is the most common chromosome abnormality in humans. It is typically associated with a delay in cognitive ability (mental retardation, or MR) and physical growth, and a particular set of facial characteristics. The average IQ of young adults with Down syndrome is around 50, whereas young adults without the condition typically have an IQ of 100. (MR has historically been defined as an IQ below 70.) A large proportion of individuals with Down syndrome have a severe degree of intellectual disability.

Down syndrome is named after John Langdon Down, the British physician who described the syndrome in 1866. The condition was

clinically described earlier by Jean Etienne Dominique Esquirol in 1838 and Edouard Seguin in 1844. Down syndrome was identified as a chromosome 21 trisomy by Dr. Jérôme Lejeune in 1959. Down syndrome can be identified in a baby at birth or before birth by prenatal screening. Pregnancies with this diagnosis are often terminated.

The CDC estimates that about one of every 691 babies born in the United States each year is born with Down syndrome.

Many children with Down syndrome are educated in regular school classes while others require specialised educational facilities. Some children graduate from high school, and, in the US, there are increasing opportunities for participating in post-secondary education. Education and proper care has been shown to improve quality of life significantly. Many adults with Down Syndrome are able to work at paid employment in the community, while others require a more sheltered work environment.”

Phocomelia

“Phocomelia (from Gr. φώκ|η ph^hōk|ē, “seal” + ο interfīx + μέλ|ος mēl|os, “limb” + Eng. suff. -ia) is an extremely rare congenital disorder involving malformation of the limbs (dysmelia). Étienne Geoffroy Saint-Hilaire coined the term in 1836.

Although various numbers of factors can cause phocomelia, the prominent roots come from the use of the drug thalidomide and from genetic inheritance. The occurrence of this malformation in an individual results in various abnormalities to the face, limbs, ears, nose, vessels and many other underdevelopments. Although operations can be done to fix the abnormality it is difficult due to the lack of nerves, bones, and other related structures.

Thalidomide was released into the market in 1957 in West Germany under the label of Contergan. Primarily prescribed as a sedative or hypnotic, thalidomide also claimed to cure “anxiety, insomnia, gastritis, and tension”. Afterwards it was used against nausea and to alleviate morning sickness in pregnant women. Thalidomide became an over the counter drug in Germany around 1960, and could be bought without a prescription. Shortly after the drug was sold, in Germany, between 5,000 and 7,000 infants were born with phocomelia. Merely 40% of these children survived. Research also proves that although phocomelia did not exist through the 40’s and 50’s, when thalidomide was released in Germany in the 60’s, cases of severe phocomelia multiplied; the direct cause was traced to thalidomide. The statistic was given that “50 percent of the mothers with deformed children had taken thalidomide during the first trimester of pregnancy.” Throughout Europe, Australia, and the

United States, 10,000 cases were reported of infants with phocomelia; only 50% of the 10,000 survived. Thalidomide became effectively linked to death or severe disabilities among babies. Those subjected to thalidomide while in the womb experienced limb deficiencies in a way that the long limbs either were not developed or presented themselves as stumps. Other effects included: deformed eyes, hearts, alimentary, and urinary tracts, and blindness and deafness.

A genetic disease is inherited by an individual from the genes provided by their mother and father. Depending upon the grouping of these genes for a particular trait, determines whether or not an individual will inherit a certain disease. According to National Organization for Rare Disorders (NORD): when phocomelia is transmitted [in its familial genetic form] it is seen as an autosomal recessive trait and the mutation is linked to chromosome 8.

Recessive genetic disorders occur when a person receives identical “abnormal genes” from both the father and mother. If a person inherits one normal gene and one gene for the disease, the individual will become a carrier for the disease; however, they normally do not show symptoms. The chance for two carrier parents to both supply the defective gene and produce a child with symptoms is 25 percent with each pregnancy.

During normal cell division, each chromosome is replicated and the original chromosome is attached to the new copy. Although there are several attachment points in a chromosome, the centromere is the major connection point and where the immensity of the work generates. The chromosomes’ connection allows the cells to join together—making sure that the two copies are “lined up together at the center of the dividing cell.” Once the chromosomes are aligned, tiny molecular spindles attach to each copy and then pull away the “original and new copy” as the division continues. An individual containing phocomelia will have chromosome copies that do not connect at the centromeres, making them unable to line up accordingly. As a result, the cell becomes incapable of division or slow in the process; because of this the newly made cells contain an excessive or reduced amount of chromosomes. In phocomelia the cells cease to develop, or die, preventing proper development of the limbs, eyes, brain, palate, or other structures.”

Conjoined or parasitic twins

Conjoined twins

“Conjoined twins are identical twins joined in utero. A rare phenomenon, the occurrence is estimated to range from 1 in 50,000 births to 1 in 200,000 births, with a somewhat higher incidence in

Southwest Asia and Africa. Approximately half are stillborn, and a smaller fraction of pairs born alive have abnormalities incompatible with life. The overall survival rate for conjoined twins is approximately 25%. The condition is more frequently found among females, with a ratio of 3:1.

Two contradicting theories exist to explain the origins of conjoined twins. The older theory is fission, in which the fertilized egg splits partially. The second and more generally accepted theory is fusion, in which a fertilized egg completely separates, but stem cells (which search for similar cells) find like-stem cells on the other twin and fuse the twins together. Conjoined twins share a single common chorion, placenta, and amniotic sac, although these characteristics are not exclusive to conjoined twins as there are some monozygotic but non-conjoined twins that also share these structures in utero.

The most famous pair of conjoined twins was Chang and Eng Bunker (Thai: ช้าง-อิง, In-Chan) (1811–1874), Thai brothers born in Siam, now Thailand. They travelled with P.T. Barnum's circus for many years and were billed as the Siamese Twins. Chang and Eng were joined by a band of flesh, cartilage, and their fused livers at the torso. In modern times, they could have been easily separated. Due to the brothers' fame and the rarity of the condition, the term "Siamese twins" came to be used as a synonym for conjoined twins.”

Parasitic twins

“A parasitic twin (also known as an asymmetrical or unequal conjoined twin) is the result of the processes that produce vanishing twins and conjoined twins, and may represent a continuum between the two.[citation needed] Parasitic twins occur when a twin embryo begins developing in utero, but the pair does not fully separate, and one embryo maintains dominant development at the expense of the other. Unlike conjoined twins, one ceases development during gestation and is vestigial to a mostly fully formed, otherwise healthy individual twin. The undeveloped twin is defined as parasitic, rather than conjoined, because it is incompletely formed or wholly dependent on the body functions of the complete fetus. The independent twin is called the autosite.”

Cyclopia

Although I decided I don't want to have a baby with a great deformation on face, I picked this genetic disease. The reason is that I saw (in pictures and photographs, not in the Anatomy Museum to be true) fetuses with cyclopia, whom were quiet normal except, they didn't have nose and they had just one eye. I picked this disease because of the Greek story of Odysseus and the one eyed giant. Later

I find out that those fetuses are rather (really) distorted, but at that time I already had a sculpture of one of them.

“Cyclopia (also cyclocephaly or synophthalmia) is a rare form of holoprosencephaly and is a congenital disorder (birth defect) characterized by the failure of the embryonic prosencephalon to properly divide the orbits of the eye into two cavities. Its incidence is 1 in 16,000 in born animals, and 1 in 250 in embryos, one in 2,500 that end in miscarriage.

Typically, the face is either missing or replaced with a non-functioning nose in the form of a proboscis. Such a proboscis generally appears above the central eye, or on the back, and is characteristic of a form of cyclopia called rhinencephaly or rhinocephaly. Most such embryos are either naturally aborted or are stillborn upon delivery.

Although cyclopia is rare, several cyclopic human babies are preserved in medical museums .

Some extreme cases of cyclopia have been documented in inbred farm animals (horses, sheep, pigs, and sometimes chickens). In such cases, the nose and mouth fail to form, or the nose grows from the roof of the mouth obstructing airflow, resulting in suffocation shortly after birth.

Genetic problems or toxins can cause problems in the embryonic forebrain-dividing process. One highly teratogenic alkaloid toxin that can cause cyclopia is cyclopamine or 2-deoxyjervine, found in the plant *Veratrum californicum* (also known as corn lily or false hellebore). The mistake of ingesting *Veratrum californicum* while pregnant is often because hellebore, a plant with which it is easily confused, is recommended as a natural treatment for vomiting, cramps, and poor circulation, three conditions that are quite common in pregnant women. Cyclopia can occur in the womb when certain proteins are inappropriately expressed and causes the brain to stay whole instead of forming into two distinct hemispheres, which also means one optic lobe and one olfactory lobe resulting in one eye.

Shh (Sonic Hedgehog Gene Regulator, named after the effects a mutation in the gene had on the forming embryo of fruit flies studied by scientists; a spiky appearance under a microscope, similar to that of its video game character namesake) is involved in the separation of the single eye field into two bilateral fields. Although not proven, it is thought that shh emitted from the prechordal plate suppresses Pax6 which causes the eye field to divide into two. If the shh gene is mutated, the result is cyclopia, a single eye in the center of the face (Gilbert, 2000).”

8.7 Materialize

The actual sculpting had to start after the choosing. I thought, also, that during the creating more babies my non existing sculpting skills should develop. I was asked a few times; why it is me who is making the sculptures? Why didn't I asked a professional to make the sculptures by my plans? Why am I not using a 3D printer to print the babies? I wanted to gather some knowledge about sculpting. I was curious, if it is possible for me to do it or not. I was curious how materials are working. Against 3D printing there was the reason of not wanting to sit next to the computer all day-I think I spend more hours next to the computer than I should. Above all these reasons, I thought that if the statues are made by hand, by my hand the outcome must contain a part of me. The outcome would be more personal.

The first problems appeared with the first tries of sculpting.

I didn't know anything about the materials, but my ideas were for the materials of the outcome of the statues; porcelain, ceramic, silicone. For all of those materials a prototype was needed for making molds. The prototypes must have been made. Finding a material for this was first a challenge. I started with clay. It seemed to be an authentic sculpting material. The fact that it could be bought in 10 kg packs also made me think that this must be the material for the first ones. The drying and petrifying worried me before the clay try out started. Fortunately my worries were needless. I didn't get to the point to dry or petrify the clay. After I bought a quite an amount of clay and worked with it for a few hours I realized that it won't work for me. I couldn't make nice lines out of it, the clay was breaking and above all it was too hard for my hands. After a few hours of work I couldn't feel my hands any more. I needed so much and intense strength that my unprepared hands couldn't deal with it.



After some thinking I said to myself, it is going to be my diploma work, I had to find a good material, it couldn't depend on its price. The next try out was the one material which I knew before, the plasticine. I like the smell of the plasticine and it was rather easy to create nice sensitive forms out of it. I still really like plasticine, but for that purpose it wasn't the right one. I couldn't handle it in big. It was braking all over. In little details it was good, I could have make nice eyes line, those parts which were not broken had nice smooth surface. But still it wasn't good.



Then I tried out another product of Fimo. An air drying kind of clay. The surface wasn't that nice, it was a bit rough, the little lines were too harsh, but it was working. With the Fimo I faced to the problem of not enough knowledge about sculpting. I realized that every face, which is made by me, has the Down syndrome kind of look. Maybe the attempt that I wanted to make the face cute turned it to a Down syndrome face. I know, huge fashion companies are using little Down syndrome models, because they are like little elves.



In this point of the material trying I started to think about someone who could make my statues for me. I started to feel really mixed up and helpless. The only fortunate thing was that there were still some untried materials on the shelves of the art shop.

Papier mache was the next material. Long years ago I tried to make doll heads out of that material. It wasn't a successful try. I mixed together the powder of the masche and the water and it was flowing. And it didn't dry at all. The most structured form out of it was a noodle with eyes.



Accidentally I find the material which was good for my project at the end. It was again a papier mache. But it wasn't a powder, it was premixed. It is smooth, soft, easily shaped, and not so expensive, although I had to travel a lot to find a shop which had that material. I find out a technique how I can make the statues not just from this material, but create a main body out of paper and duck-tape and foil, than the papier masce comes.



This worked, the only challenge was still the sculpting. My sculptures were nice, but for most of friends they were more creepy than nice. I noticed that my skills developed during the sculpting. I studied how a nice baby looks like. I studied where are the eyes on the face? What is the position of the nose, what kind of forms are the most specific?

Now the prototypes are ready. They are waiting for the silicone molds to come and the silicone pouring. They are going to get eyes, they should be at the end more living like than now with the died color of grey.

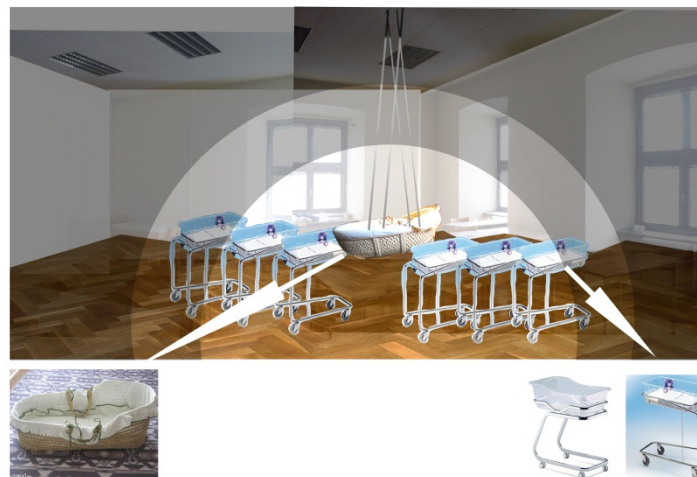






Set up

One question left, it was the set up. First I imagined a fully furnished baby room and the strange babies playing, laying around. It would have been really like a freak show. Next idea was to push the project into the science side. With Petrie dishes, white colors, clean hospital like set up.



The question was: what I want to say with the babies?

After a few try out I decided that they have to fly (hung) in between earth and sky, they have to be fragile and shiny. They have to be similar like little saints in pictures. Some little signs, like little pair of shoes, little dresses should be around, but just to be a sign of a normal child.

9 Raison d'etre

My project is unfinished before the exhibition. I could make comments and conclude the project, but the correct conclusion about The Package project could just come after exhibiting my statues. However I can describe some reaction from my friends which were made during working on the project. These were important just to see how someone might react.

At the start I was rather amazed by the idea of the package project. It was a huge cloud of thoughts, so I felt right to speak about it, because every talking cleared my thoughts a bit. For my surprise my talking partners were not so amazed by my topic. I've got comments which were questioned the topic as it was a must? Was it a decision made by a professor of yours? When I cleared that no, this idea comes from my head, they were astonished. "But, why are you doing this?" -Was always the question. "It is like dealing with gipsy children and handicapped children at the same time and a little earth pollution too"- Could have been my answer, but my answer wasn't ever that short and solid. I tried to tell the whole conception again. Sometimes I had really inspirational talks with friends whom had individual questions and thoughts about having a disabled child or have a not so nice art piece at home. But after most talking my talking partners had the idea that "she is dealing with gnomes!" or "she is dealing with something rather fishy...". The worst comment from a friend of mine(a close friend)was that: "Please don't start to talk about your diploma thesis, leave it till when we finished eating.." -We were in a cafe with friends and all the others didn't know anything about my work at all. With writing down these comments I haven't got an attempt to show that I'm a" not understand by the rest of world artist". I just had to realize that the topic of mine is more than unwelcome for more people than I thought. The comments also changed my point of view to the project. I started to feel confused if someone asked me about my project. I decided more not to talk about it, because it was always a long discussion. I got in the situation that in the eyes of my friends not just my project seemed to be strange, but me too. I think somehow the project generated itself. I wanted to talk about how people can't cope with strangeness and how hard it must be for a parent to cope with the fact of having a disabled child. The parent might feel that it is her fault, the child is a result of her not being enough. The same happened with me, I started to feel, that my project told to the others that something is not right with me. So as a parent I acted the worst way from all the ways which I could have been acted. Only my collages and rather open minded friends were not shocked and only they could take the project as a result of thoughts and not as a result of me having some problems.

I'm looking forward to the exhibition. I would like to see my project ending and also I'm rather curious if some of the visitors would take home my babies.

My offer is that instead of a garden gnome adopt a disabled baby!
For an art work lifetime is while it is exhibited. An art works lifetime
is when public is there. The raison d'etre finishes for an art work
which is packed away as a package.

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