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## Applying principles of Information Design to help parents accept babies with Down syndrome

Anita Eradla  
*Virginia Commonwealth University*

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Welcoming Babies with Down syndrome







With deep affection and admiration, this project is dedicated to babies with Down syndrome and their parents.



**Applying principles of Information Design to  
help parents accept babies with Down syndrome**

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MA Advertising & Public Relations  
Madurai Kamaraj University, Tamilnadu, India, 2001

BS Genetics  
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MFA Visual Communication  
Virginia Commonwealth University, Virginia, USA  
Creative Project, May 2006



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Submitted to the faculty of the School of the Arts at Virginia Commonwealth University, in partial fulfillment for the requirements for the degree of Master of Fine Arts in Visual Communication.

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## Abstract

My creative project is a system of resource materials designed for parents and expecting parents to promote acceptance of babies with Down syndrome. This project is also a study of information architecture and icon development, and an opportunity to study the universal and emotive qualities of an iconic system.



## Introduction

Science has been an intriguing subject to me. I always wondered and still question how I came into this world, how things are always changing around me. Where I belong and what I share with the unknown. The changes I have personally been through have made me think and rethink my surroundings. I have always seen painting and graphic design as an outlet to my emotions and understanding of things.

Prior to this project, I created diagrams to help myself understand things around me, from my day-to-day schedule to long-term goals. I remember how I planned defense or offense strategy while playing hockey at school. For my aero-modeling hobby I recollect making my own interpretation of model plane engines to understand a way to start them. Even more important is how diagramming helped me get through my undergraduate work. Genetics was my educational focus prior to VCU, with additional study in Chemistry and Zoology. The drawings from zoology and chemical structures from chemistry helped me understand these subjects in a clearer way. My texts in Genetics lacked such clarifying visualizations, so I had to come up with my own methodology of understanding them. I drew my own diagrams to understand the process involved.

I believe that my creative project combines this background interest in science with my passion for design.









## Problem Statement

As I was growing up I saw children around me who I knew were somehow different—but not only because they had a unique look. They definitely touched me emotionally. Some were my friends' siblings and some were in my family. These children had speech problems and it was difficult for them to communicate and for others to communicate with them. Though they were loved they were also isolated by many because they were different. Most of my questions about them were answered while I was studying Genetics. To find more information I continued researching this condition known as Down syndrome. Through my research, I learned that this is the most prevalent of genetic mutations, affecting 1.3 in 1000 live births. Although Down syndrome is very common, the resources currently available that educate new parents in accepting their babies with Down syndrome are a collection of outdated and insensitive materials. They lack answers to important issues including what causes this condition, how to take care of the baby, and social implications after a child is born with this condition.

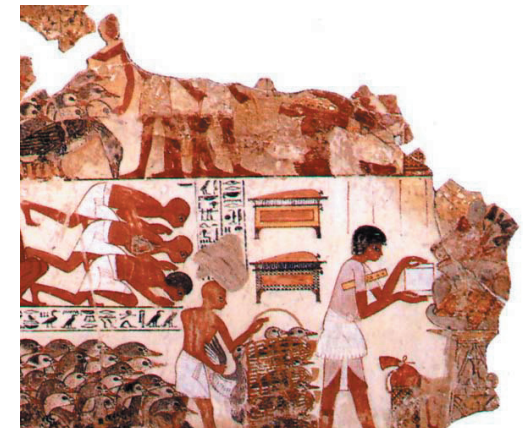
With no cure yet it is important to encourage more understanding.

## Information Design

In order to reach my audience with a balance of information and compassion, I researched the many approaches and attitudes toward Information Design to form a theoretical basis for this project. According to information designer Nathan Shedroff, "Information Design is a field and approach to designing clear, understandable communications by giving care to structure, context, and presentation of data and information. As a field, its principles relate to all communications products and experiences, regardless of medium (print, broadcast, digital, online, etc.). Information Design is, primarily, concerned with clarity (instead of simplicity) and understanding."<sup>1</sup>

Only in recent years has Information Design been recognized as a unique discipline. However, it has been practiced for as long as people have had the need (and the means) to communicate information to one another.

Beginning with the first Egyptian scribes who composed the daily records, memos, and proposals for their marketplace clients, the business of assisting others to make communications more effective has flourished. Specialists in communications abound in our society: ghost writers, technical writers, advertising writers and art directors, public relations writers, and marketing consultants are only the most obvious ones. In any field of human endeavor there is first specialization followed by increasing professionalization. Information Design is the most recent manifestation of the age-old profession of communications assistance.<sup>2</sup>



Egyptian scribes at work ( [www.luther.edu](http://www.luther.edu) )

Information Design is not only important—it is essential. Understanding information in our complex modern society requires a lot of time and patience. We now have access to information almost everywhere through various media like the web, advertising, and books; but simply storing large amounts of information, doesn't solve the problem of information access. In fact, it complicates the process. Sometimes trying to find specific information leads us through so many non-related topics that we find ourselves lost in the information jungle.

While researching information about people with Down syndrome and their families, I came across information about the science and economics of developing new pharmaceuticals for rare genetic diseases and population screening for genetic conditions. I found very little information about how such developments would affect the lives of people with these conditions. Though the results from this research were way off my initial topic, it convinced me further of the need to design information for understanding.

Information only has value when it is successfully communicated. Remembering this will help in promoting understanding. If the information cannot be accessed or understood it does not have value.



Where's Waldo? book illustration

Today, Information Design is such an integral part of our world that sometimes we have trouble recognizing it. It's completely entangled with the way we process our environment. It is like the *Where's Waldo?* books which cultivate a way of seeing in the "reader" (more like "audience", as there is no text). The audience becomes attuned to certain visual patterns, enabling them to pick out Waldo from a busy illustration.<sup>3</sup>

Similarly, Information Design helps cultivate a way of seeing that allows us to pick out the right message from the busy informational landscape of modern life.

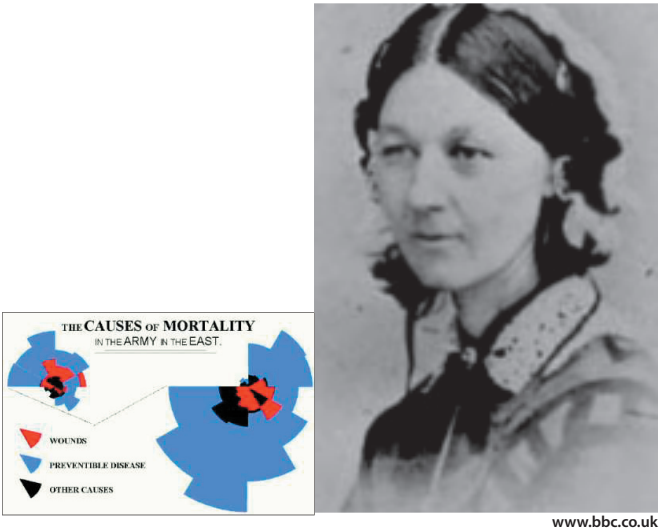
In his article *Information Design: The Understanding Discipline*, designer Dirk Knemeyer states, "the notable characteristic of Information Design is the broad range of fields that associate themselves with it. There are meaningful groups within graphic designers, writers and information architects that all make some claim to the term Information Design. Typically, disciplines are easy to define in at least a basic, tactical way. Graphic designers provide visual solutions. Writers provide written solutions. Information architects provide structural design solutions. Information Design ostensibly comes down to a broad set of information deliverables, not any single type or particular component of other disciplines."

He adds that "Information Design is the integrator that brings other disciplines together to create excellent information solutions."<sup>4</sup>

Information Design addresses high-level information problems to provide maximum clarity, understanding and effectiveness. It is not important what tools are used to achieve it, but rather that the final deliverable provides the greatest possible degree of understanding. In order to achieve that ambitious end, Information Design must be open to all disciplines or fields of thought. It must also encourage the use of systemized processes for the design of successful information, synthesizing the established processes in the myriad of information disciplines.

Additionally, Information Design must actively encourage and participate in research that increases our understanding of information and its effects: how and why people respond to information, how the human brain processes information and builds knowledge, as well as how humans organize knowledge and convert it into improved behavior and operation. Better understanding of these factors will enable us to create the best possible information understanding.

Some of the examples from my research that do not follow any rules other than clarity of communicating information allowed me to recognize the flexibility that Information Design offers to the designer. "The Causes of Mortality" graph by Florence Nightingale is one such example that has always caught my attention with its simplicity and clarity in message. The diagram makes the complex statistical data from the Crimean war easy to read and understand.



Statistical graph by Florence Nightingale  
In this diagram, the blue wedges, representing death by sickness, are far bigger than the red wedges representing wounds. The message of this graphic is twofold: first, most of the fatalities during the war were from sickness; and second, improvements in hygiene dramatically reduced the death rate.

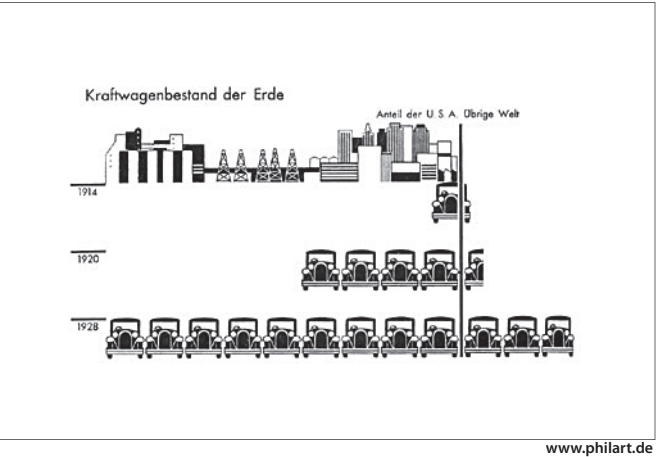


The display of pictorial statistics by Otto Neurath portray good examples where Information Designs enables understanding by visual education.

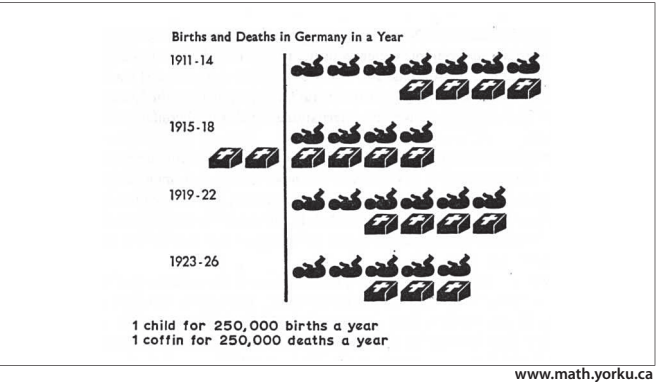
ISOTYPE (International System of Typographic Picture Education) Images.



18 typical, statistic picture with ISOTYPE



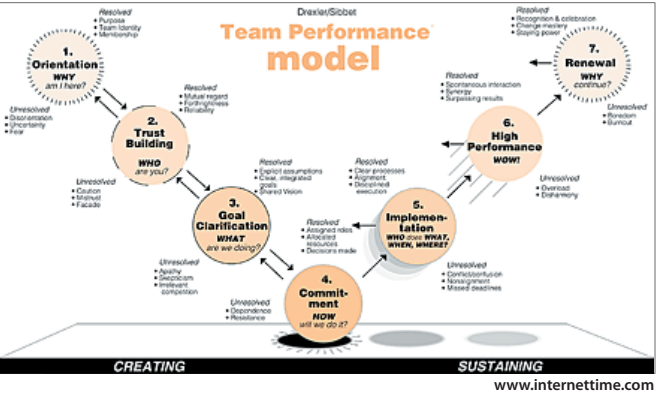
Births and Deaths in Germany in a Year



Following statistical Information Design was conceptual Information Design. In 1980 David Sibbet devised a set of techniques for graphically recording the process of group dynamics as they develop during a meeting.

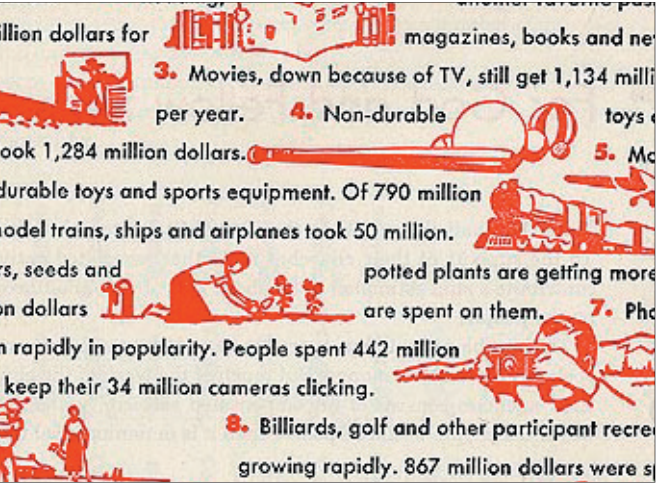
The flexibility and success of Information Design has given hope that a purely visual communication, without the use of words, would become an international auxiliary language.

Rudolf Modley’s use of abstracted and the figurative symbols is another source of inspiration for me, because these symbols can be used over and over again in different contexts and sometimes have more meaning than the words. These visuals have the power to create recognition and memory within the experience and helps to communicate and retain the message. I had a similar intent for my project and saw the possibility of using images in my approach.



David Sibbet Model

The purpose of this model was to make it possible for people to have constructive dialogues with each other and come to some common understandings that can serve as the basis of important decisions.



USA IN NEW DIMENSIONS

Thomas Carskadon & George Soule, Macmillan 1957  
Graphics by Rudolf Modley  
Source: <http://www.fulltable.com/iso/rm/rm.htm>

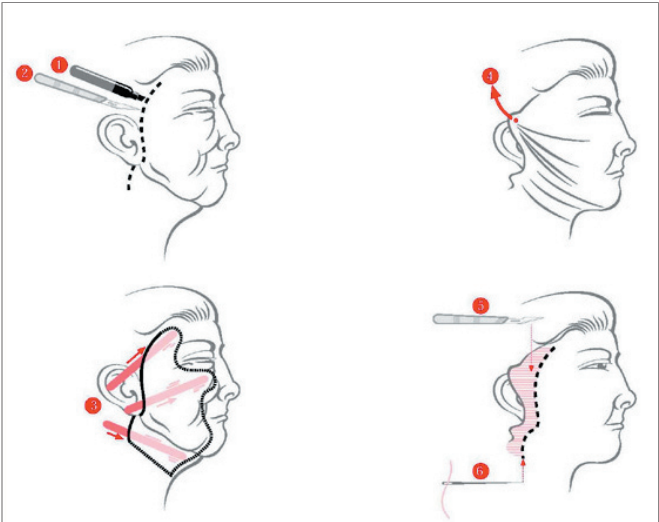
My intention became much stronger while doing research about my audience. As part of my process I interviewed a couple of doctors and genetic counselors who told me that new parents whose children are diagnosed with Down syndrome prefer not to read anything. In such a state of denial, comforting visuals would be a good option to pursue.

With this important information, I continued researching more about symbols and icons used in Information Design.



Olympic symbols for Munich by Otl Aicher

I was reminded of the icons used for the Olympic symbols. These have always amazed me with their unified style. The first Olympic symbols for Munich by Otl Aicher have a unique formal language and I am inspired by how easy they are to identify and read.



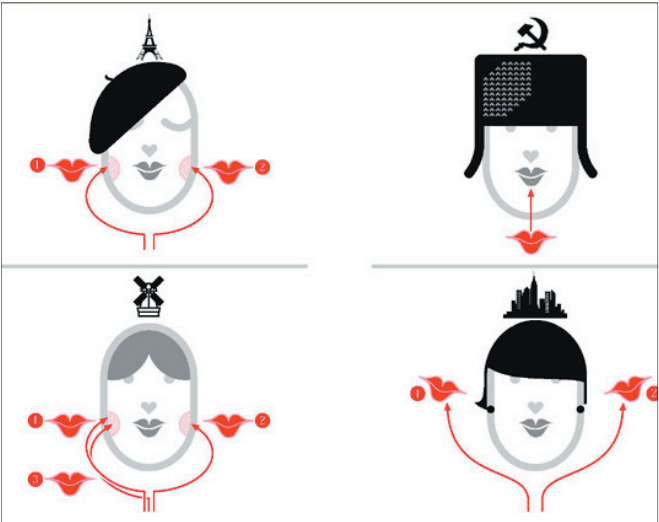
How to do a facelift

I am also inspired by the work of Nigel Holmes. His approach in explaining simple tasks with pictorial images makes it interesting and attractive for the reader. I believe that this design attractiveness makes a message more appealing and appear to be less of a challenge or a “test” for the audience.

Information Design goes beyond just information display, serving to also educate and promote understanding. The emphasis on communication is also concerned with what content is to be communicated and in what form.

In reference to the examples of Information Design, the real problem in my project is the absence of form. With so much content already available about Down syndrome, the absence of form creates a lack of effective communication and becomes a significant Information Design problem.

Sir Tim Berners-Lee, founder of the World Wide Web and author of *Weaving the Web* writes: “The world can be seen as only connections, nothing else... A piece of information is really only defined by what it’s related to, and how it’s related. There really is little else to meaning. The structure is everything.”



How to greet someone in various countries

Drawing relations between the existing content and its failure to communicate the message to it’s audience (parents) encouraged me to design a structure and a system of forms that not only educates but also produces an immediate reaction (of a parent’s acceptance or denial of baby with Down syndrome). This study formed the core of my project and I began to investigate and experiment, through designing icons.

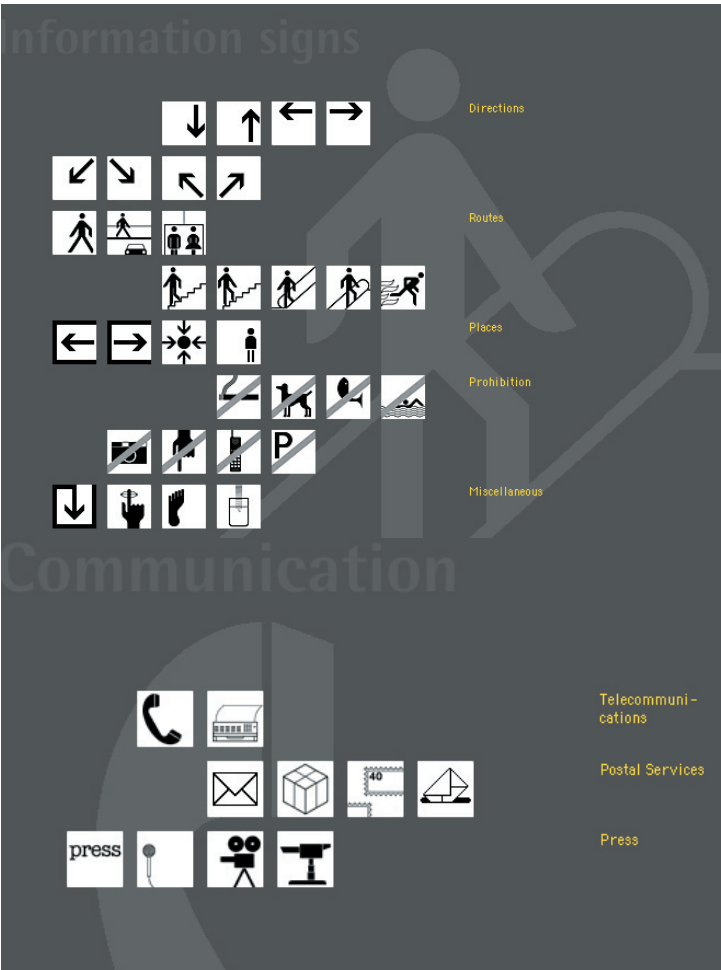
Why icons?

I am interested in the communicative and emotional qualities in icons. An icon (from Greek word eikon, “image”) is an image, picture, or representation; it is a sign or likeness that stands for an object by signifying or representing it, or by analogy, as in semiotics; in computers an icon is a symbol on the monitor used to signify a command; by extension, icon is also used, particularly in modern popular culture, in the general sense of symbol — i.e. a name, face, picture or even a person readily recognized as having some well-known significance or embodying certain qualities.<sup>5</sup>These characteristics make icons powerful and help in conveying a large amount of information quickly.

Traditionally, the use of icons has been limited to communicating traffic signals, directions, routes, places, prohibitions, postal services, telecommunications and press.

With my project I have tried to employ icons to communicate the message of acceptance of babies with Down syndrome to parents. To design such icons I had to address two underlying sub-problems: how to educate parents who come from different ethnic groups and, how to craft it’s message for parents who are in denial of the diagnosis.

Designing icons to evoke emotions is something I have never done before. Making them linguistically and culturally neutral both in terms of the content and form was an interesting challenge.



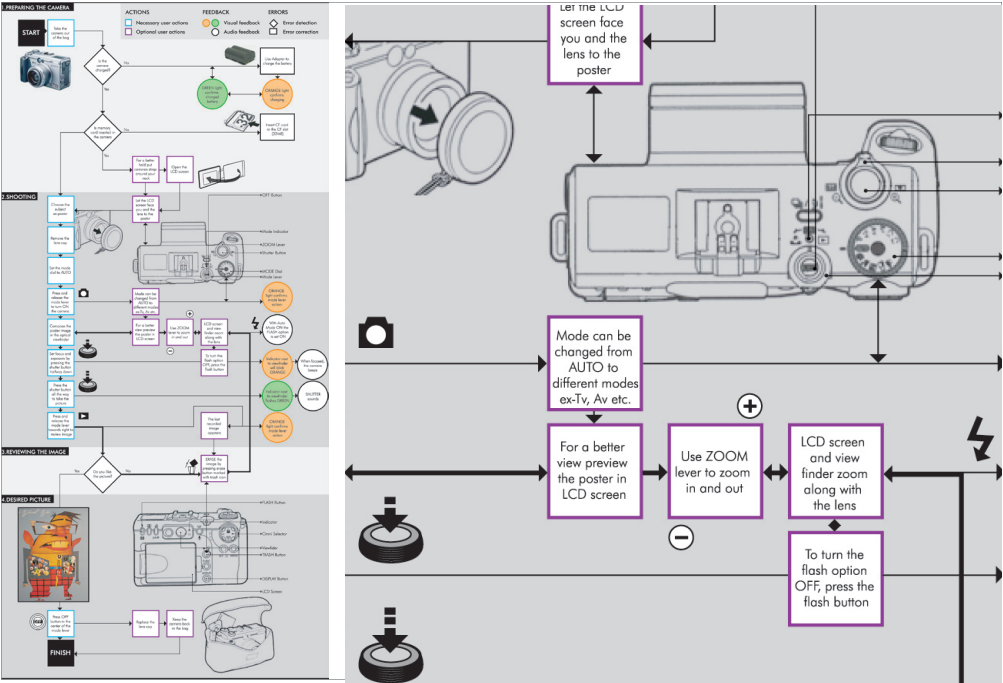
Traditional use of icons in communicating traffic signals, directions, routes etc



Precedents

Past projects  
In my two years of graduate school, I had the opportunity to work on many interesting projects and when I look back I see a number of projects that have been directly or indirectly pivotal to the development of my creative project.

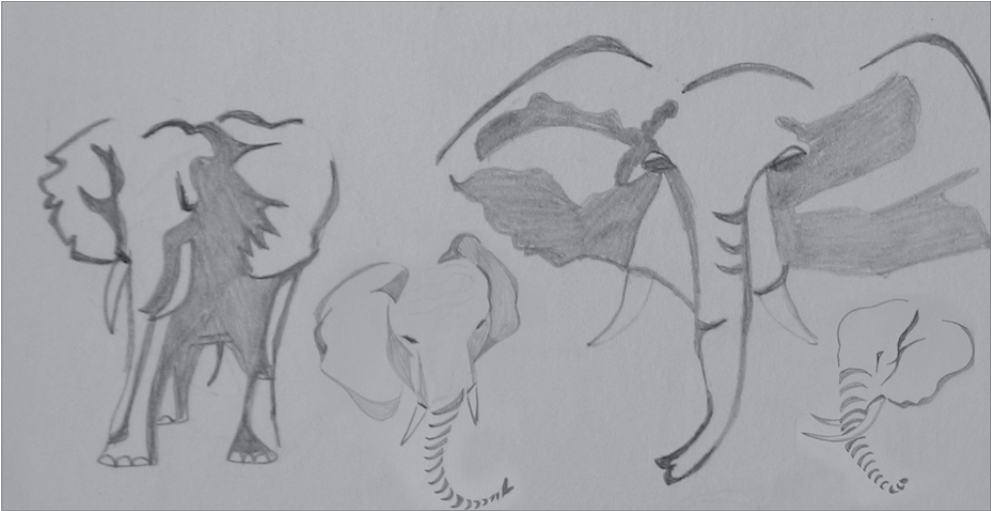
Roy McKelvey, Fall 2003  
**Diagramming experience.** In this project, we were asked to document and design an experience of taking a single picture from a digital camera.



This project helped me organize information and introduced me to the use of successful word and image combinations, and how they can effectively communicate complicated technical steps using simple solutions.

Janet Horst, Fall 2003  
**CRY visual identity project.** This project started with choosing our favorite animal and I chose an elephant. We were then asked to design a mark with few details but without losing the identity of the animal. The real challenge was to apply the mark to a welfare organization to create a visual identity. I enjoyed the unpredictability of this approach, because I previously approached design with the final solution in mind.

The elephant, when hurt or in pain, raises its trunk and that helped me to assign the mark to CRY (Child Relief & You) organization, which provides underprivileged kids education and shelter.



Susan Roth, Fall 2004  
**Obesity awareness project.** This project was to create awareness about obesity in children. This being a very sensitive issue, I had to be very careful in presenting the facts without hurting anyone. The design of a visual identity had to be simple and clear. I experimented with alphabets and icons that replaced the letter "O" in obesity with mother (blue icon) and child (yellow icon) highlighting attention to care for children.

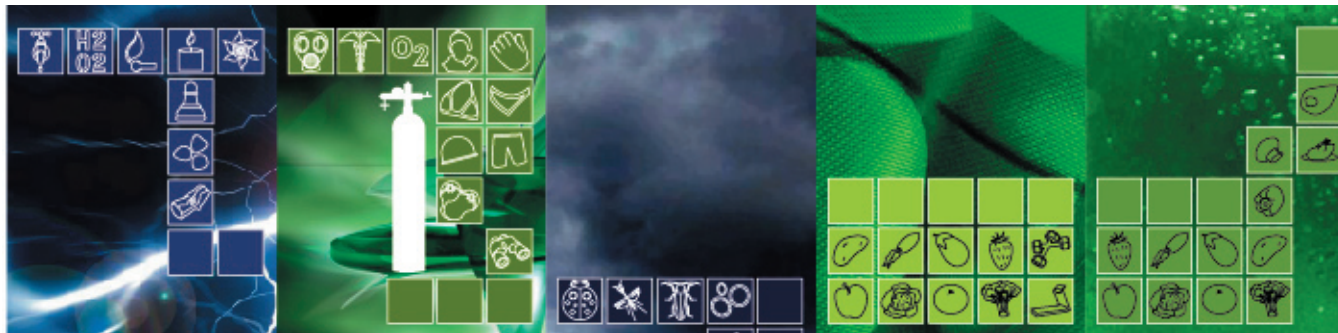
This project helped me to design icons conceptually based on the idea that parents should take care of children.



*John Malinoski, Fall 2004*

**Nature's challenge project.** This is the first project where I initially started designing icons. In this project, I proposed a hypothetical vending machine for future when all the natural resources are lost, except this machine has all we would need. It is highly advanced and would carry things from food, oxygen, medicines, oil, taxis, buses, treadmills etc. The machine would not have anything written on it since it is highly impossible that the survivors will be English speaking only. Hence, to communicate to a larger audience I proposed icons for each object. The following are some of the examples.

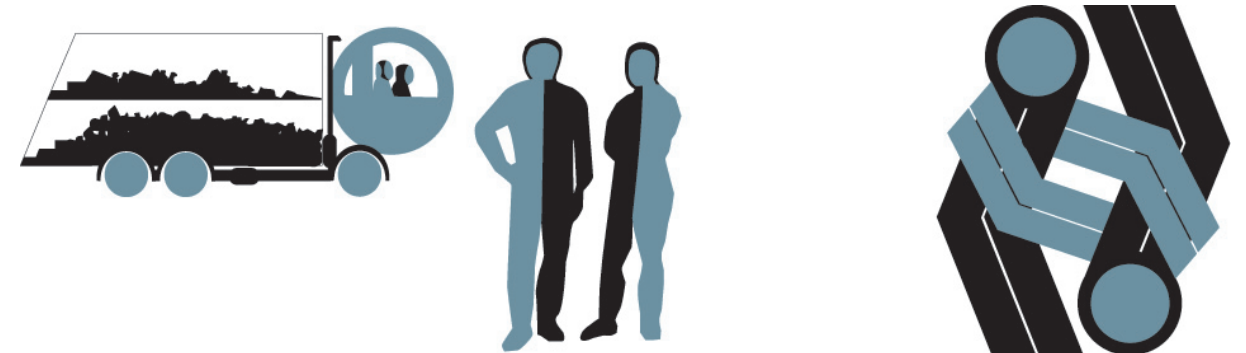
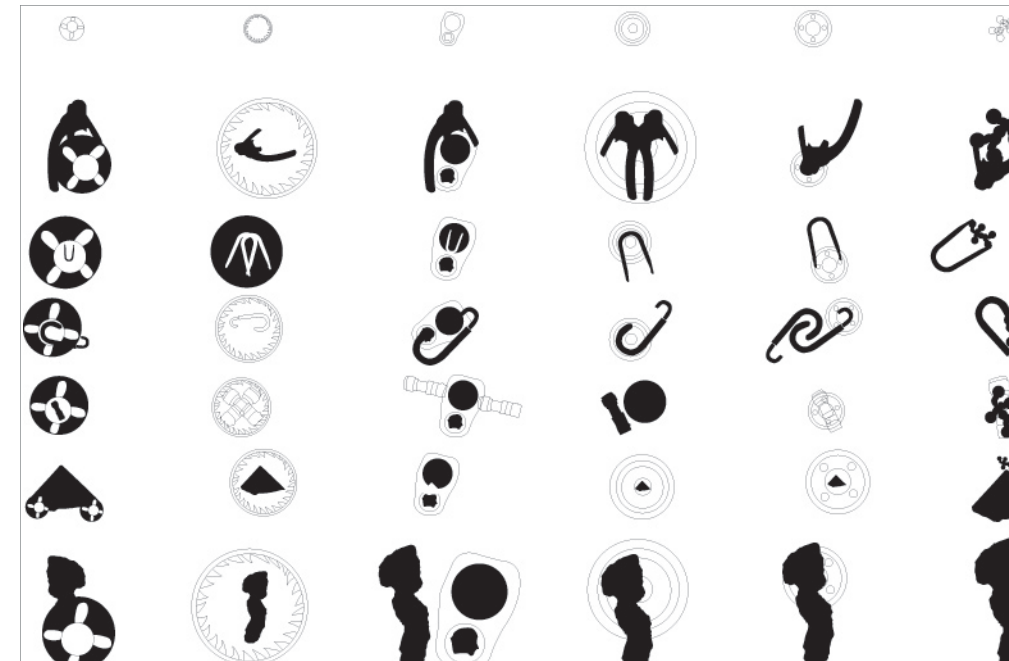
This project helped me to design icons that were simple representations of actual objects.



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*John Malinoski, Fall 2004*

**Recycling project.** In this project, we were asked to develop an identity mark for a new recycling program in the city of Richmond. The process involved was very interesting. We began by collecting objects found on the ground, a collection that grew quickly ranging from small coke caps to large iron rods. We were then asked to divide the objects into two groups, and set up them up in a matrix where an object from one group would be formally merged with each object from the other group. These unusual juxtapositions yielded unique results and challenged us to think differently about identity marks.

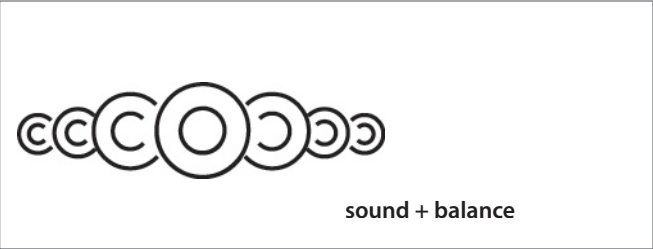


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Laura Chessin, Spring 2005

**PunarUpyog project.** This project was to create an identity mark for a recycling organization. The mark was inspired by Hindu mythology's elements of life—earth, water, fire, air and sound, which are also responsible for birth, death and regeneration. The icons were designed to represent each individual element and were the conceptual and abstract representations of the same.

This project helped me to understand the possibility of communicating more than one idea through icons. For example, the Fire icon represents fire and transformation. The Earth icon represents earth and growth. The Fish icon represents water, fish and movement.



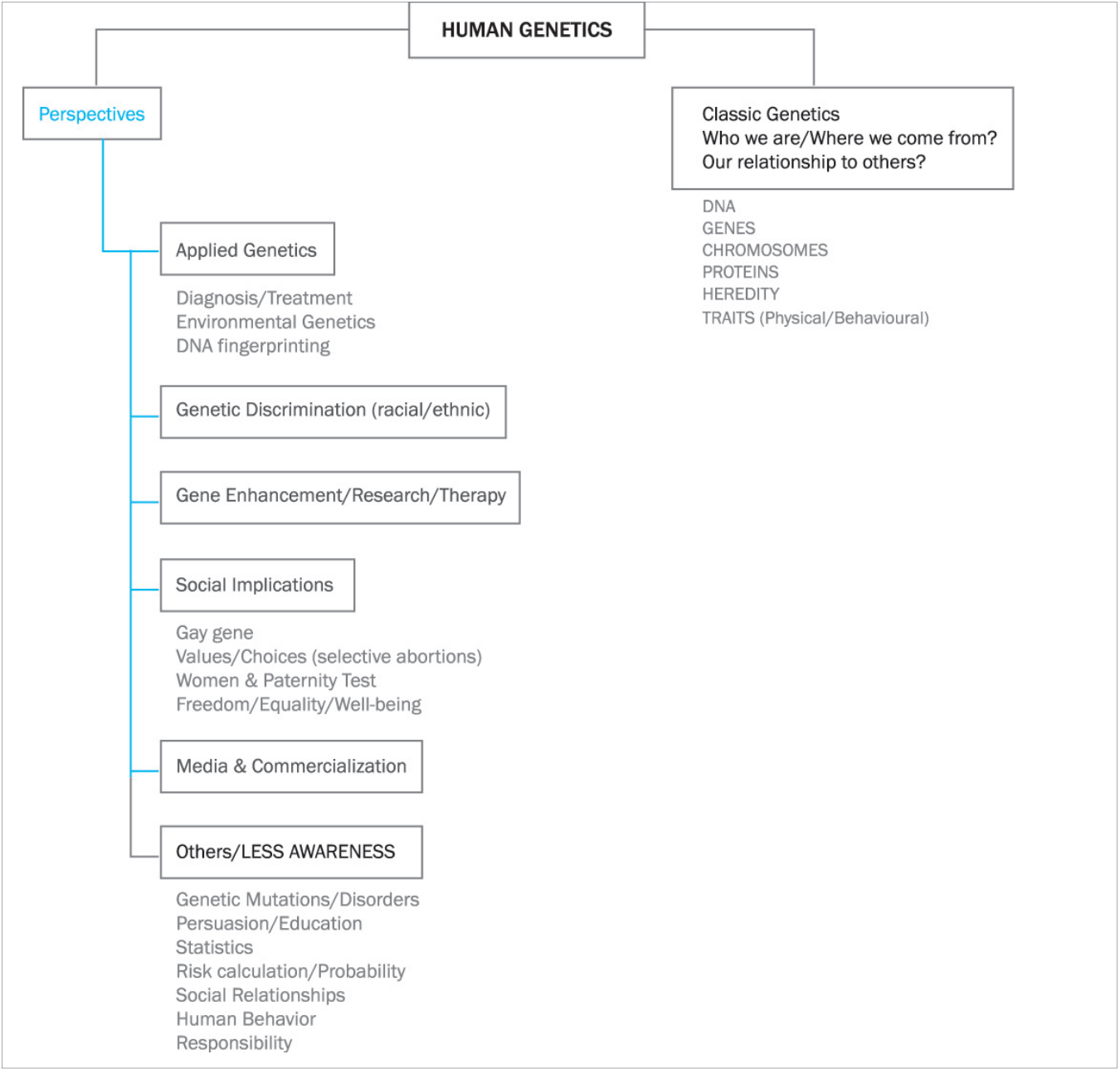




Before commencing the form of my project I started organizing the information I had gathered from various sources.

As I found information related to my project, I would organize it into a series of diagrams and visuals that would help me understand it better. My initial organization involved putting together the common perspectives about genetics. This was important to make myself understand what people generally knew about genetics prior to being informed about Down syndrome.

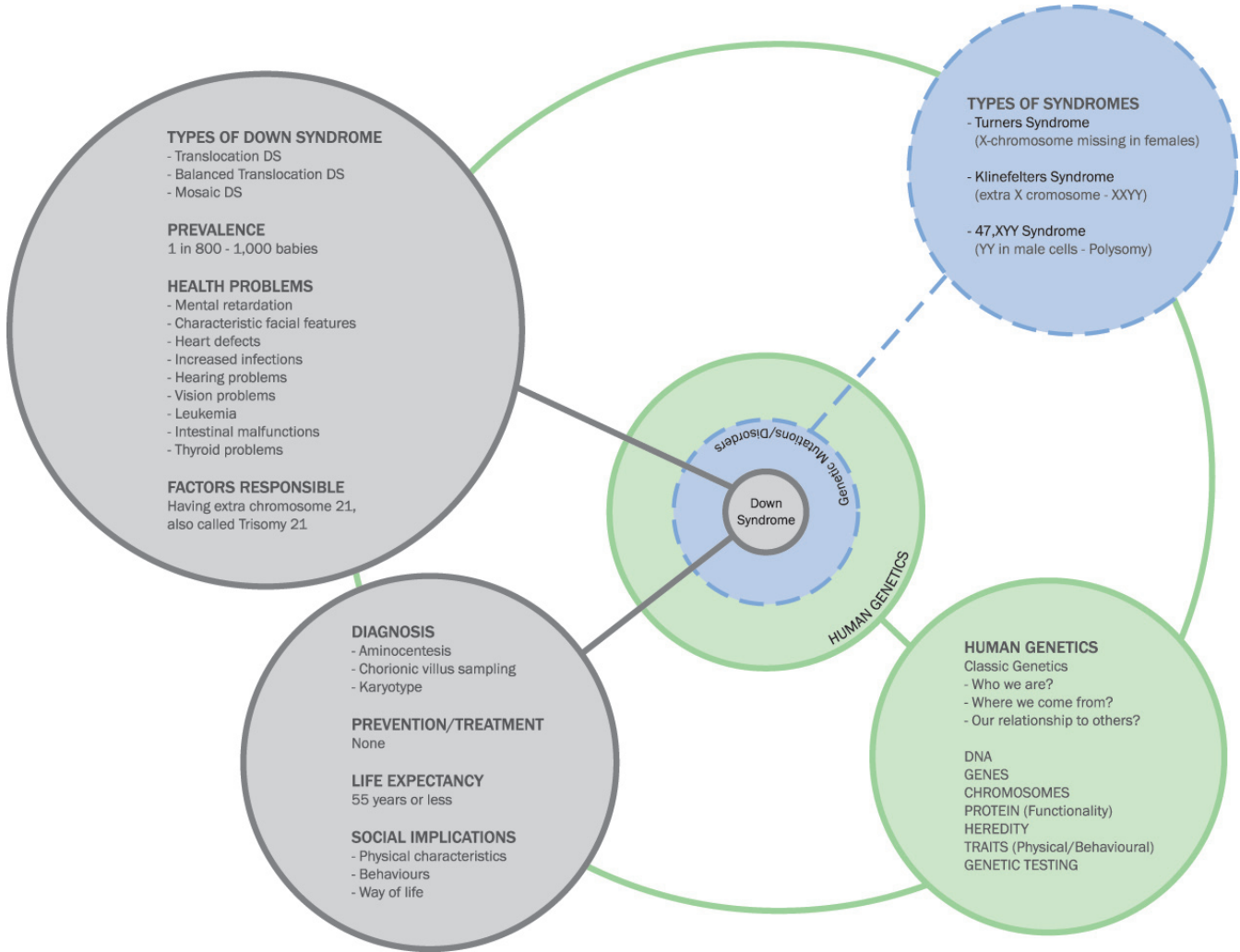
Common perspectives about Genetics.



I continued my process with mapping Down syndrome in a diagram and it helped me to highlight important information about the different types of Down syndrome, it's prevalence, health problems, factors responsible for this condition, life expectancy, diagnosis and social implications after a child is born with Down syndrome.

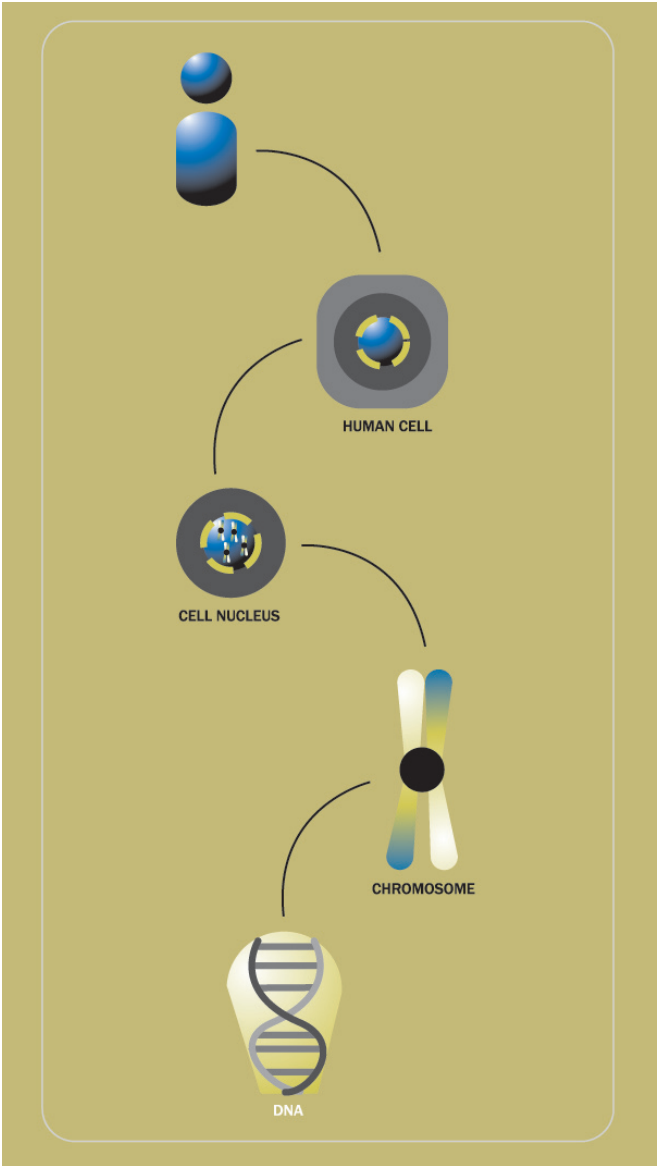
Mapping Down syndrome

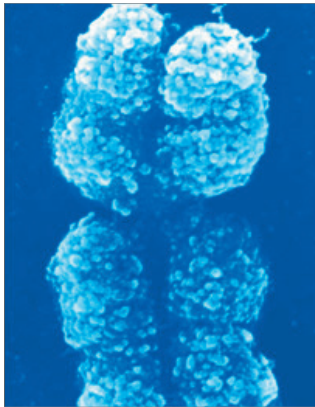
This information model helped me approach the design of information in parts for clearer understanding.



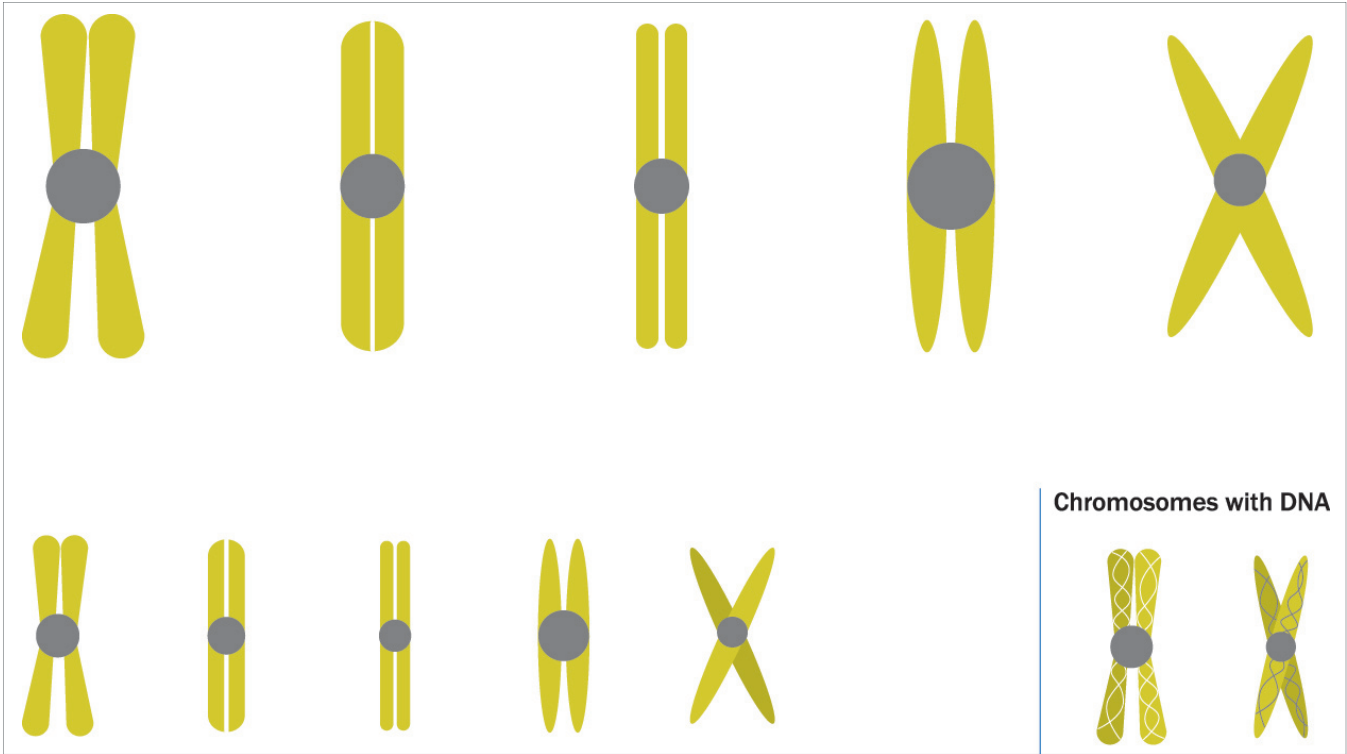
As I moved ahead in my process, I realized a lot of questions and information related to Down syndrome were scientific and it was important to explain them in a simple terms for a non-scientific audience. To do so, I opted for pictorial explanation for easy understanding. My initial designs around these series were answering questions like: What is a DNA? How does a chromosome<sup>6</sup> look like?

What is a DNA?

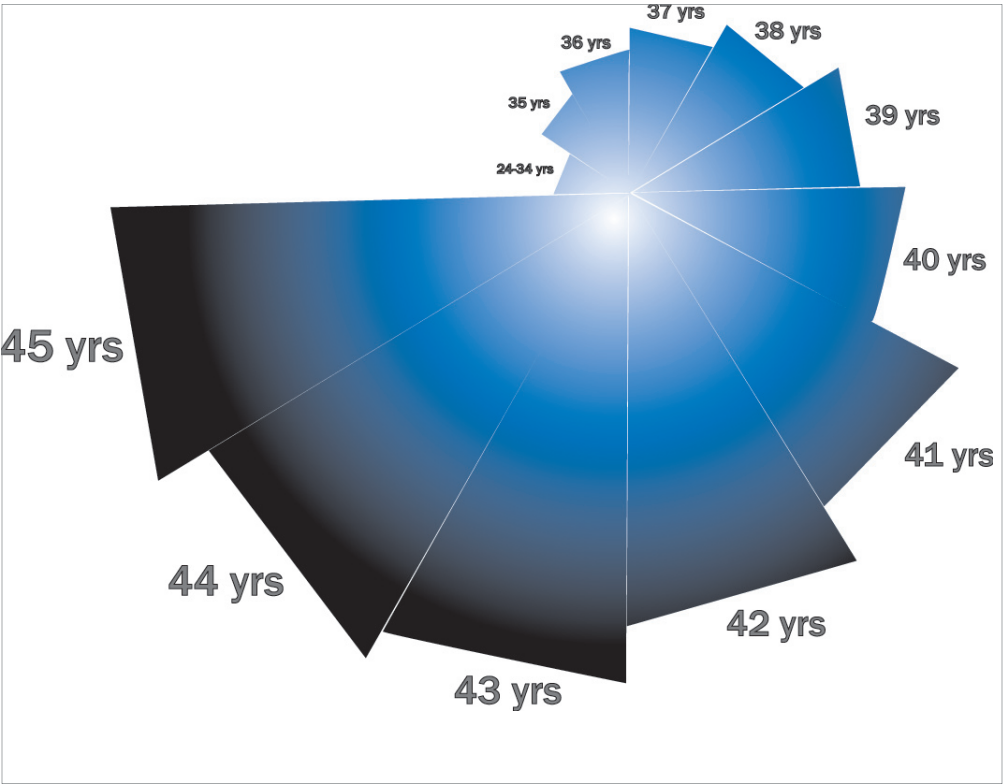




electronic microscopic image  
source:www.bbc.co.uk



In the process I also took some real data and designed Information around statistics. The following probable risk diagram was the result of such data and is inspired by Florence Nightingale’s “The Causes of Mortality” diagram. Here I visually tried to show the increasing risk of having babies with Down syndrome with the increase in mother’s age.

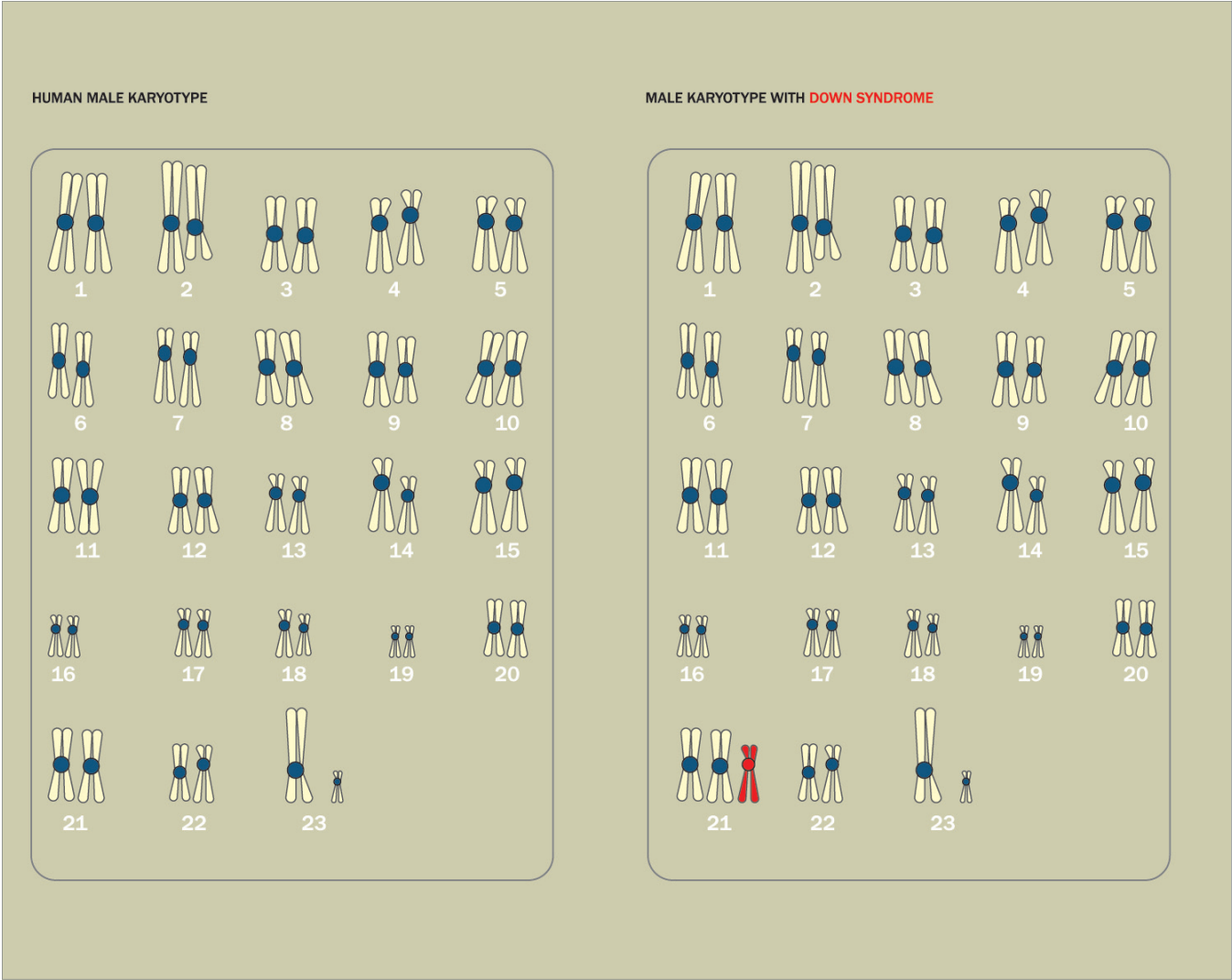


Though I was happy with its clarity in communication, I realized it moves away from my main objective for the project. My intentions are to create understanding about Down syndrome for new parents and not to show them Information when they have already been diagnosed with the condition. It would prove important to educate the probability of risk factor only when they are interested—probably before diagnosis. This clearly justifies the principle of Information Design where right information should be delivered at right time or else its may loose its purpose.

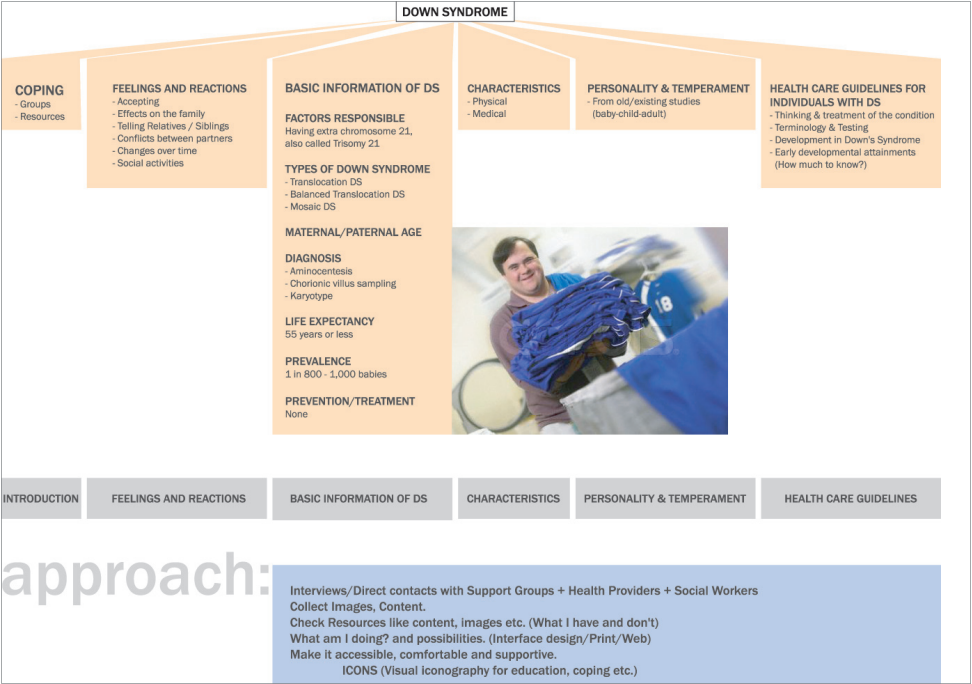


I next concentrated on information design that would create an understanding about Down syndrome and facilitate acceptance as a new parent. In scientific terms, Down syndrome is classified as having an extra chromosome. Instead of words I tried to explain this with visuals showing the extra chromosome in a healthy chromosome karyotype. A karyotype is the complete set of all chromosomes of a cell of any living organism. The chromosomes are arranged and displayed (often on a photo) in a standard format: in pairs, ordered by size. Karyotypes are examined in searches for chromosomal aberrations.

Human Karyotype



Architecture of the project

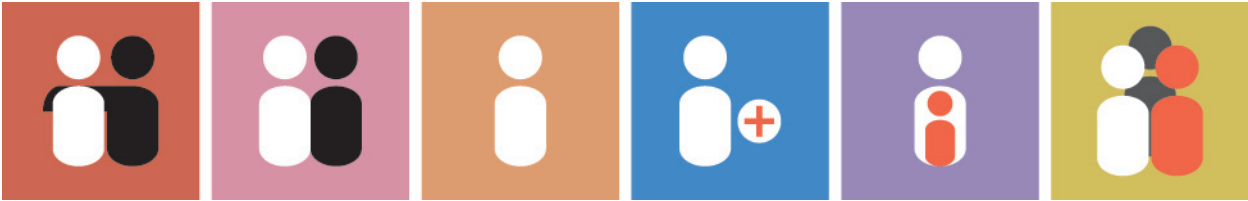


Continuing with the idea of communicating information in parts, I categorized the main topics into six parts, starting from when parents first learnt about the diagnosis. Following this is acceptance of babies with Down syndrome, feelings and reactions, basic information about Down syndrome, the physical and medical characteristics of the new baby, temperament of the baby, healthcare guidelines and medical treatment for the baby.

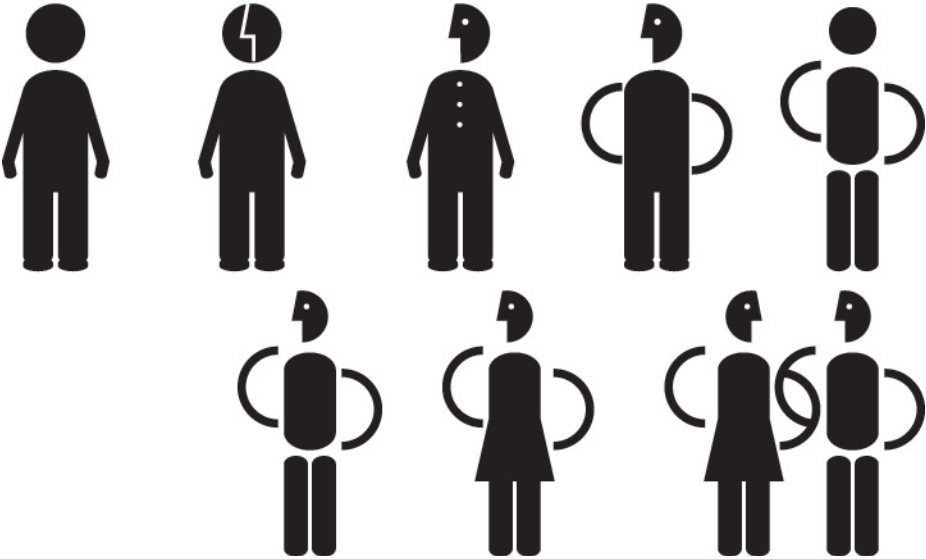
The more I worked with content and pictures I agreed with Otto Neurath's ideas. Pictorial statistics operate with spatial- temporal objects. In worded language, it is possible to use meaningless connections which often are only removed with effort. Words carry more emotional elements than quantity pictures which can be grasped without objection by people from different countries and parties. Words separate, pictures unite.

This thought lead me to use pictorials to represent each part of communication for a much clear and sensitive approach. For each category of information I designed an icon. Initially it was to distinguish them from one another and also for easy access to particular information. But while doing further research I learnt that in Richmond many parents of babies with Down syndrome come from different ethnic groups and to communicate to these different groups of people, I started designing different icon designs. I believe the icons possess emotive qualities and have the power to transcend the language barrier.

**Set 1** – These icons are the first set, I designed these around universal symbol of male icon. I believed making it simple will help communicating the idea better and by adding color they became more effective in catching attention and helped in approaching the message sensitively.

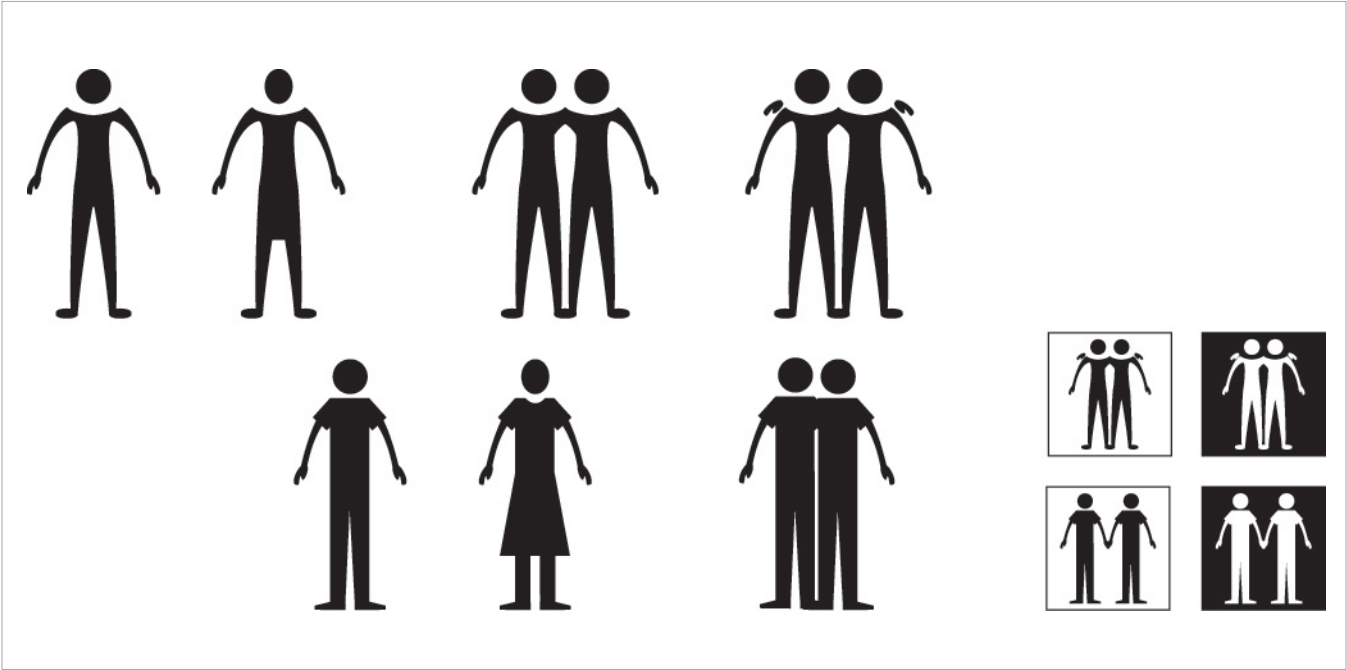


**Set 2** – In this set, I tried to add emotions to the icons by drawing physical and facial features. I wanted to see if I would be able to make them more dynamic in actions by moving their hands and changing expressions.



Until now I have never really designed icons communicating comfort and understanding. This became a real challenge for me. I enjoyed experimenting with them from really abstract forms to human like.

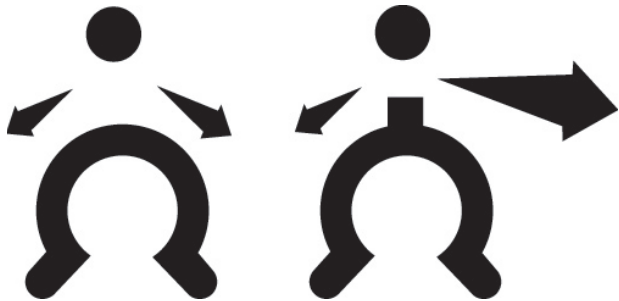
**Set 3** – This set was another experiment with more distinctive hands and legs. From here I started to experiment with male and female icons. I started with the generic idea of distinguishing them by their clothes.



The more I worked with these icons, the more I wanted to push myself into different possibilities.

A deliberate condensed presentation of selected human features led to the development of following icons studies.

**Set 4**

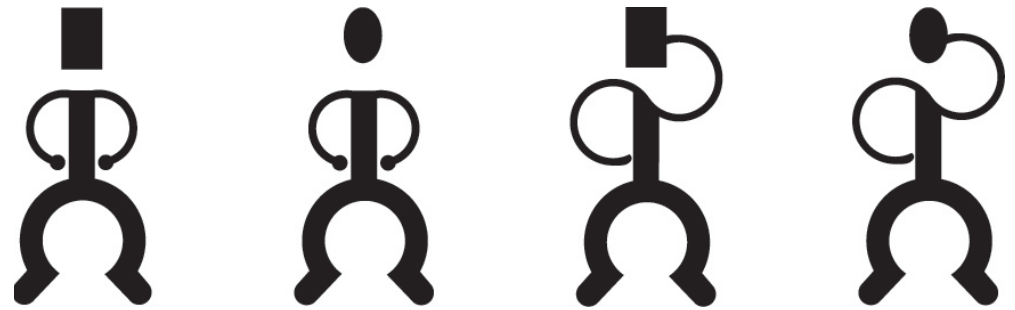




Set 5



Set 6



Set 7



Set 8



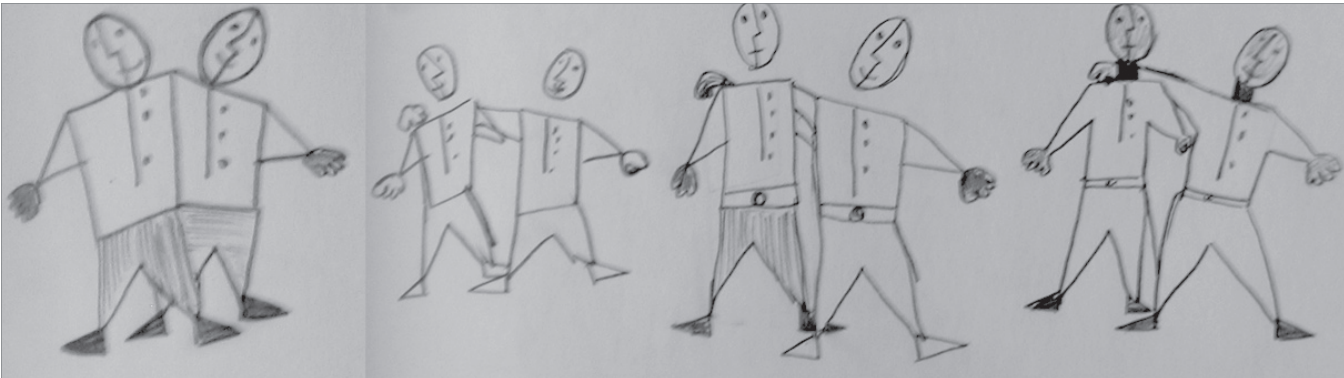
With more experimental icons, I felt the abstract forms deviated from my intent to communicate comfort and understanding at the same time.

My attempt to make these icons resemble Down syndrome individuals was not successful either. Too much resemblance made them appear to mock the condition and I decided not to continue with this approach

Set 9



**Set 10** – With this new set, using an expressive face to interact with the reader also felt out of context. They were designed to create awareness about Down syndrome but looked too cheerful for new parents who are already angry and in denial about the diagnosis.



With a tough challenge ahead I couldn’t think beyond what I had so far. I wasn’t sure which approach I should be taking now and felt stuck. During this time I had the opportunity to present my project to a group of doctors, Genetic counselors and Genetic counseling students. When I showed them the icons, they responded positively. They made immediate connection with Set-1 saying they reminded them of chromosomes. They also liked the use of colors.

At the same presentation I wanted to have an expert opinion on the requirement for designing the information resource for new parents. I handed over a small survey created for this purpose to get their feedback.

**Survey 1** – The responses from survey were helpful, but mixed reactions towards the icons and need for resources did not help me much in making a decision about the icons.

One of the leads from this presentation helped me to get contact information of a parent of a baby with Down syndrome who introduced me to DSAGR (Down Syndrome Association for Greater Richmond).

At DSAGR, I got the opportunity to present my topic to a group of parents of babies with Down syndrome. The age of the children ranged from newborn to adults aged 26 years. This was a very unique opportunity for me to learn from their practical experiences and incorporate them in my project. I handed out small survey asking important questions about their first reaction, prior awareness, and effectiveness of available resources.

**Survey 2 – responses from parents.**

How did you first learn about your baby having Down syndrome?

*We learned that our daughter had DS when she was 4 months old and was not gaining weight. The Doctor said she was close to “failure to thrive” and blamed it on my breast milk – the asked us to feed her by bottle almost force feed her – we did that for several weeks and she gained a few ounces. The doctor suspected DS and did the testing and confirmed it. He called us in and announced it to us and told us to be happy it was not ADD or ADHD.*

*The pediatrician came into my room about 3 hours after my daughter was born and said that he noticed characteristics that could indicate Down syndrome or some other genetic abnormality.*

*The moment I held her I knew. When I asked the Dr. about it, she said that she would be performing some tests, so she recognized it immediately also.*

*That I wanted to give the baby up for adoption*

What was your first reaction?

*We were totally unprepared and shocked and quite a bit concerned about raising a child with DS because we knew so little about it. I think that’s natural given that neither my wife nor I had ever dealt with a person with DS. Having time to research the condition and its challenges, we felt much better.*

*Disbelief and then grief and sadness*

*Immediate devastation and then just fear of the unknown.*

*Fear! I had no idea what DS was except those people I saw at the local ARC near my gym. It scared the heck out of me because quite frankly I did not know where to begin or how to take care of my son. The second reaction was God could only give you what you can handle. Also my brother-in-law immediately put it in to perspective for us when he said that God must think you are very special people to give you a gift in Konor.*

What material was provided to inform you about Down syndrome?

*Old outdated information that suggested institutions and other outdated information, all very negative.*

*A very large very hard to understand binder of info from the Hospital.*

*Shelley is 16 years old, and I don’t remember what was given to me. The hospital did give me*

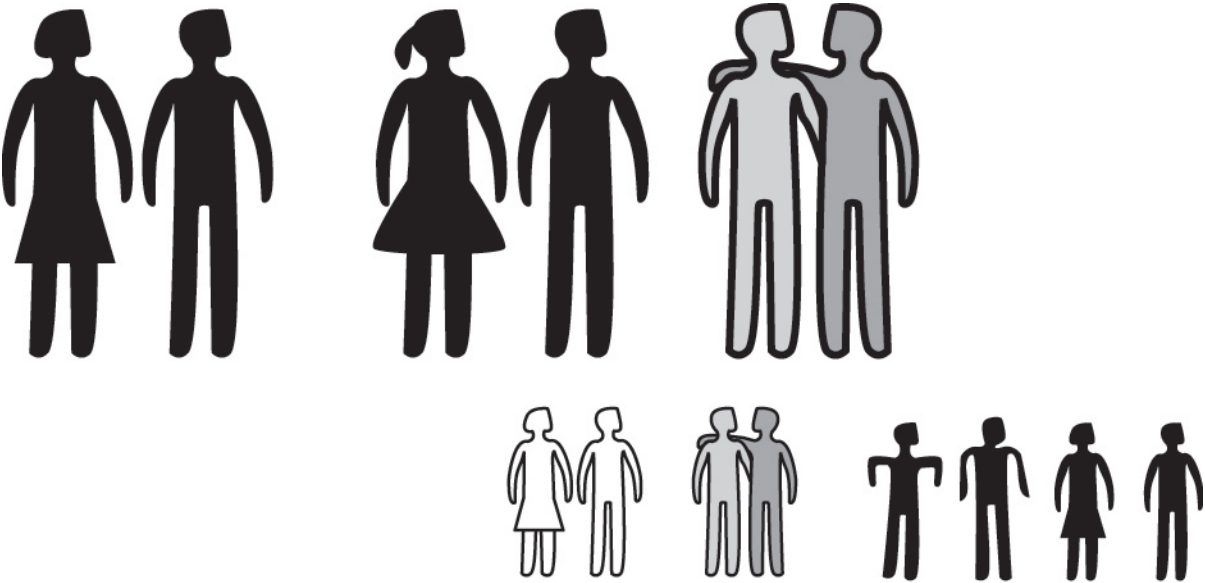
some pamphlets about Down syndrome, but I was not in the mood to read at that point.

I don't recall the hospital where Becky was born or MCV Genetics Department, where she was seen shortly after birth, providing any memorable or useful materials. I do know MCV showed us a really outdated video. It would be helpful for OB's and hospitals to keep some copies of "Babies with Down Syndrome" on hand to give to families receiving this diagnosis parentally or at birth, and some materials from NDSS, NDSC, or even DSAGR (which also has a free new parent packet that is available upon request). It would be great for OB's and hospitals to tell new parents about the local DS group, DSAGR, and also keep a list of families who have kids with DS and are willing to talk with and meet new parents. Giving parents accurate, up-to-date information AND a personal connection to another family would make a tremendous difference in the lives of so many new parents!

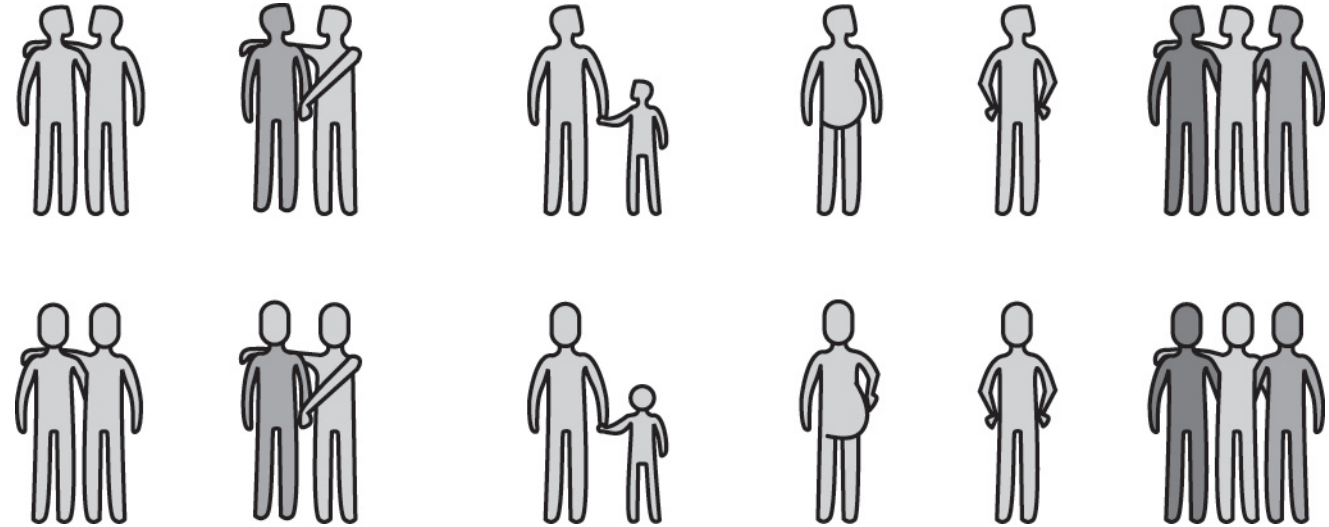
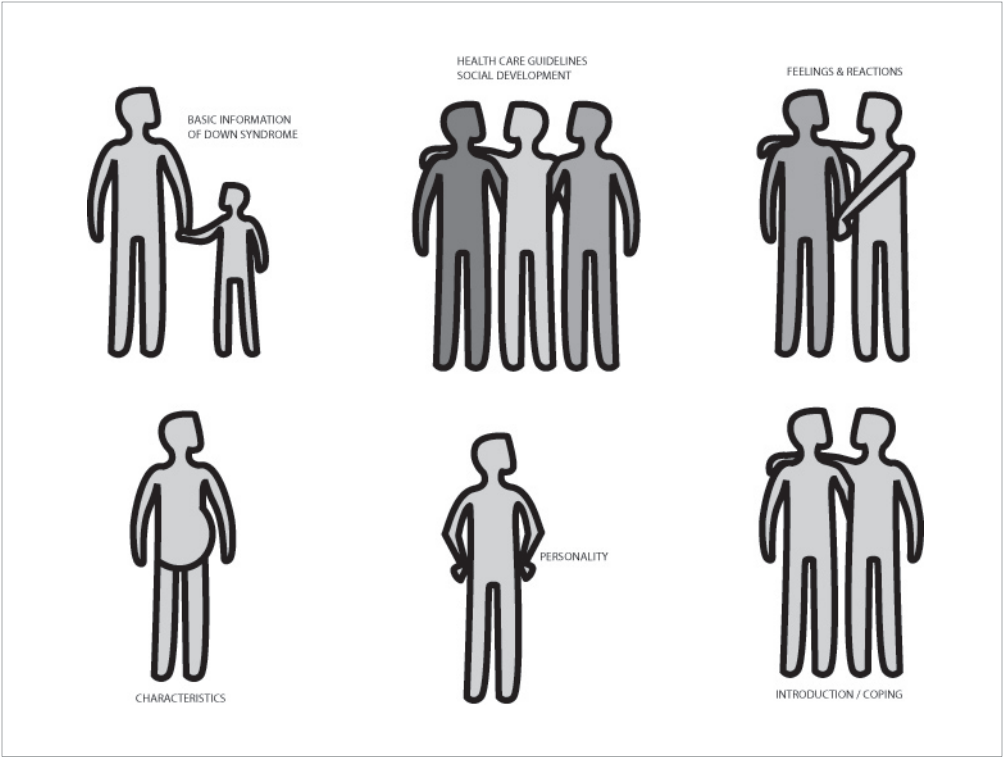
I was surprised the way doctors had approached such sensitive issues. Also the lack of first hand materials made it hard for parents to understand and accept Down syndrome. These responses further strengthened my belief in the real need for designing information for new parents that would help them accept babies with Down syndrome.

The parents' responses to the icons were very encouraging, and they responded strongly for human like icons. They said it made the subject feel personable and the color made them feel comfortable. The icons that followed were variations of **Set 11**.

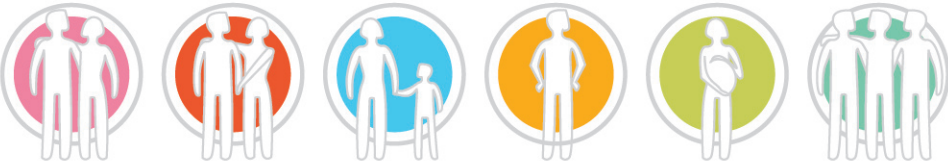
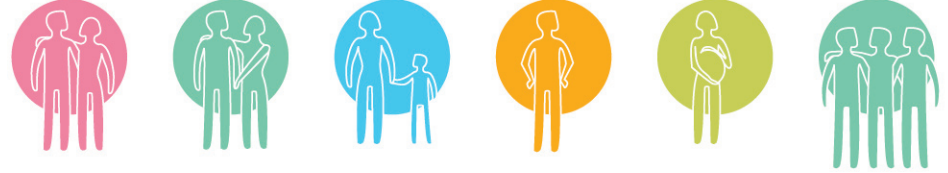
Set 11



Variations







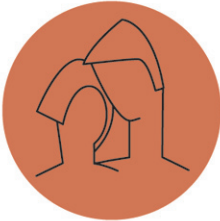
Once I had the new set of icons, I shared them with my classmates and professors for their feedback. This audience provided critical assessment of purely formal issues and a more academic and analytical critique of the relationship of form to content. They felt that not all icons looked like they were part of the system. The icons worked best individually, but as a whole they did not seem to communicate a common message.

I had to start over and come up with a set that worked together as a system. My approach to the problem was to design icons based on the content I had already gathered and organized. Retaining the human like figures and colors I redesigned them based on the steps involved in communicating the understanding about Down syndrome. I used simplified icons with outlines to eliminate clutter and also encourage clear understanding.


**Set 12** – The result of my redesign. The following chart of icon variations helped me develop the final versions.




Final set of icons




Feelings and Reactions




Acceptance




Personality & Temperament



Physical Characteristics




About Down Syndrome



Healthcare Guidelines

With the final set of icons and content complete, I wanted to make sure each icon was represented by an audience-oriented language rather than scientific terminology. I listed all the probable names under each icon and sent these to parents for their responses.

Parents agreed with most terms I had already assigned to each icon and they helped me define the final six categories as “feelings & reactions”, “acceptance”, “personality & temperament”, “physical characteristics”, “about Down syndrome” and “healthcare guidelines”.




Feelings and Reactions

- EFFECTS ON FAMILY
- TELLING RELATIVES & SIBLINGS
- SOCIAL ACTIVITIES
- CHANGES OVER TIME

DENIAL  
AGONY  
PAIN  
ANGER  
FEAR  
CONFUSION

Approach the situation




Acceptance

- RESOURCES LIKE BOOKS, DVD, WEBSITE
- SUPPORT GROUPS IN THE NEIGHBORHOOD

EMBRACE  
SHAKE HAND  
OPEN DOOR  
ACQUIRE  
GAIN  
GET  
OBTAIN  
SECURE  
TAKE  
WELCOME


Adjusting to your baby



Personality

- PERSONALITY & TEMPERAMENT OF BABY-CHILD-ADULT with DOWN SYNDROME


Family life with your baby



Physical Characteristics

- PHYSICAL CHARACTERISTICS
- MEDICAL CHARACTERISTICS
- BABY'S HEALTH
- GROWTH & DEVELOPMENT


Daily care of your baby



Basic Information

- IMPORTANT INFORMATION ON DOWN SYNDROME
- WHAT CAUSES DOWN SYNDROME?
- FACTORS RESPONSIBLE
- TYPES OF DOWN SYNDROME
- DIAGNOSIS
- LIFE EXPECTANCY
- PREVALENCE

What is Down syndrome?



Medical Treatment

- MEDICAL RESPONSE
- EARLY DEVELOPMENTAL ATTAINMENTS (HOW MUCH TO KNOW?)
- TREATMENT OF DOWN SYNDROME
- DEVELOPMENT OF DOWN SYNDROME

Medical concerns and treatments

Possible names for each icon

While thinking about possible applications I realized the content and icons could be used in any medium. For my final application I decided to design a website primarily because it can be accessed by many people at the same time and thereby fulfill the main objective of the project: to access the right information effectively and with clear understanding.

Website

Homepage of the website



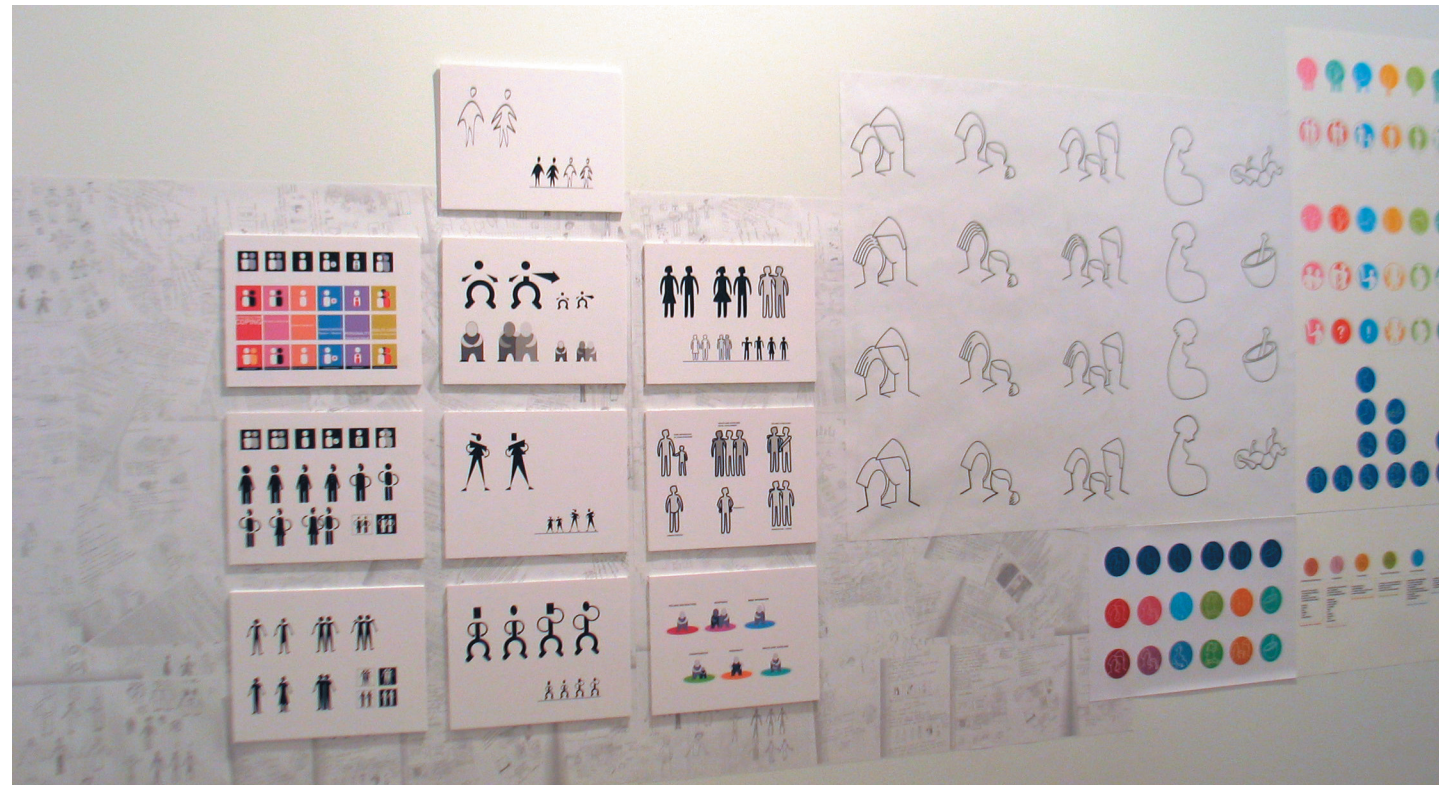
Subpage of the website







## Exhibition







## Conclusion

The most informative part of my project has been the interviews with the doctors and parents of babies with Down syndrome. I was surprised by their different feedbacks on the need for resource materials. The doctors I spoke to did not believe they needed more comprehensive materials and the parents strongly opted for more resources. The differences in the feedback made me think how sometimes the mediators of information don't realize the importance of communication and don't recognize more specialized needs. With my project I have tried to meet that need and my project has evolved from being just a theoretical project to an applied project.

The transition of my project has not only met the need for comprehensive materials but has also helped me identify my strengths as a visual communicator. This is the first time I have ventured into designing icons that can emote feelings and provide educational information at the same time. I think the use of icons in other fields of communication can be successfully applied to health care.

The positive response to my project from parents has helped me in evaluating the success of my project.



## Evaluation

With my final project I learnt about different approaches to visual communication of information. I first started my project to combine my interest in science with graphic design. With much scientific information related to genetic conditions available, not a lot was written about the people associated with these conditions. I found that there is a strong need to communicate this information to nonscientific audiences. Choosing the audience and what information to convey became the most important part of my research.

The process during this project has been a learning experience. I have a science background and I have always been carried away by the theoretical aspect of understanding things. But as a designer I felt challenged by the task of educating my audience in the most effective possible way I could. Choosing Information Design theory was an easy choice because of its flexibility and freedom in practice. The more I delved into the theory, the more it forced me to question each decision I made and thus helped me in my final project solution. This is the first time I tried to combine theory with real audience feedback to design a solution.

My initial approach to use Information Design theory helped me to consider the needs of my audience as a balance of information and compassion. The theory and historical precedents of Information Design helped me to

organize my research into relevant topics. The interviews with my intended audience revealed a genuine need for resources. These two factors slowly transitioned my project out of a theoretical framework into a capacity where it could address real world problems.

During my project I started out with a strict approach based on traditional Information Design. My intent was to explain the scientific information related to Down syndrome. My approach was to create diagrams that could answer questions about genetics and genetic mutations: what are they, where and how they occur. These diagrams were clear in information but were not open for interpretation. At this stage of my process I understood how the objective information became the primary function of Information Design. Simultaneously I had the opportunity to work with parents of babies with the condition and the more I interacted with them the more I got myself involved personally. I started to see the real need for a subjective approach over objective intentions. The parents responded more to the emotional approach and I slowly started deviating from my initial intention. I made the choice of concentrating on emotional aspects of sharing experiences, community building and breaking barriers. At this point it became difficult to bridge the gap between research and practice.

Stepping back now and looking at my creative project, I can see choices that I made that are working and others that could have been better. My choices influenced by research differed from those influenced by audience feedback. I do feel that if I had ventured into a more traditional approach it would have been a whole new exploration and an equally important project. At the time of making choices I could only choose one: a concrete application. While struggling/working to combine the research with practice I tried to apply organizational principles of Information Design to my project with the design of an icon system. The primary intention was to bridge cultural, economic and language differences thus creating a more universal message. The process involved in

designing these icons took a longer time than I anticipated. I believe the main reason for the delay was getting updated feedback from my audience. The problem of developing a consistent visual voice that addressed the specific concerns of the audience necessitated a prolonged design process.

As I got more involved with my audience and made direct personal contact with many parents, my research and discoveries led me towards an application that tried to combine information delivery with compassion and hope. The final solution, a combination of personal stories and photographs combined with the universal language of icons, helped me to think about theory as the backbone of good design practice.



Further Directions

In the future I want to push my applied project from its current subjective approach to include more concrete information such as educational data, skill sets, schooling, and development cycles. In my website I want to include more objective information that will help parents make decisions.



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### Footnotes

- <sup>1</sup> source: [www.nathan.com/ed/glossary](http://www.nathan.com/ed/glossary)
- <sup>2</sup> Robert E Horn, *Information Design: emergence of a New Profession*, 1999.
- <sup>3</sup> <http://www.jjg.net/ia/>
- <sup>4</sup> <http://www.bboxesandarrows.com/person/dircknemeyer>
- <sup>5</sup> [www.wikipedia.org](http://www.wikipedia.org)
- <sup>6</sup> A chromosome, from the Greek words (color) and (body) is, minimally, a very long, continuous piece of DNA

