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Tempo: design of an app that depicts time as a visual concept for people with Down Syndrome

Master's Thesis in Media and Interaction Design

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Contents

Preface

The following thesis is grounded on a series of observations from the author in regard of the relationship between individuals with Down Syndorne and Time perception.

The author is a student of Media and Interaction Design at the University of Bergen (Norway), has a completed a Bachelor in Computer Science at the University of Sapienza (Rome) and is currently a Interaction Designer specialized in the fields of Design for Inclusivity, Visualization Design and Innovative Healthcare Research.

Having a brother with Down Syndrome, the author has spent a significative part of his life in proximity of caretaking groups for individuals with Down Syndrome, and during such years, has gained a particular perspective on the needs and peculiarities associated with the condition.

The observations documented by the following thesis reflect such experience, as well as the experiences of friends and social operators met over the years, which have contributed with their opinions to the value of this document.

Introduction 1

1.1 Not perceiving Time

Time is essential in our everyday living.

Every single moment, we use it to find ourselves, to know what to do next and what has passed, to label events, pace ourselves, to address feared, longed and memorable moments.
Without time cognition, such instants would be nothing but elusive, volatile statuses, conditions without ins or outs, hard to be planned or to be understood in their cause-effect implications.

But time is also a quantity, and much like any other quantity, finds its value in scarcity.
Being aware such scarcity, we are driven to risk, to hurry, to try new things and to manage ourselves more appropriately.
Awareness of time, of its duration, fragmentation, speed, brings command on the use of time itself - and is key for the survival and self-management of every individual.

Yet, for some individuals the perception of time has been compromised, affecting their self-awareness, their ability to make choices as well as their expectations for daily and future life.
Such is the case of individuals who suffer from Dyschronometria.

Dyschronometria is described as the inability to perceive the passage of time, typically caused by Cerebellar Ataxia (brain damage at the area of Cerebellum) from either a trauma, a disease or genetics (respectively, causes of Cerebellar Ataxia) [1] .

Some of the most known signs of Dyschronometria are the loss of spatial awareness (inability to find oneself in space), poor short-term verbal memory (maintaining words or abstract concepts in memory), impaired focus (concentration), and only as a combined result of these symptoms, the inability to keep track of time.

Often associated with Dyslexia (although mostly in childhood and as a result of mental exhaustion) and with Dementia (that is considered both cause and effect of the condition), Dyschronometria is also extremely difficult to diagnose.

Behind such difficulty, is that clinical testing has proven to be ineffective for the condition [2] , and that to this day, very few Neuroscientists have focused on the topic of impaired time perception and awareness.

[1]: Lagarde et al. (2009), ‘Neuropsychological disorders induced by cerebellar damage’

[2]: Shibusawa et al. (2008), ‘Thyrotropin-releasing hormone (TRH) in the cerebellum’

The following thesis grounds itself on a set of observations performed by the author in relation to a display of Dyschronometric behavior in individuals with Down Syndrome, which according to performed research, is still undocumented.

1.2 What is Down Syndrome?

Down Syndrome, first identified by John Langdon Down (British Physician) in 1866, is a genetic condition that affects the number of chromosomes with which a child is born with. While it is common for children to be born with 46 chromosomes (23 from the mother and 23 from the father respectively), babies who are born with Down Syndrome experience what is called "Trisomy 21", meaning that their 21th chromosome is present in an extra copy [3, 4] .

[3]: Alberts et al. (2002), *Molecular Biology of the Cell*
[4]: Carr et al. (1995), *Down's Syndrome*

As chromosomes encode all sensitive information for the growth of an individual, such difference affects how babies with Down Syndrome are able to develop, both psychically and cognitively [5] .

[5]: CDC (2021), *Facts about Down Syndrome | CDC*

Individuals with Down Syndrome are often identified by common physical features, often not debilitating, such as:

- a flattened appearance (especially in the bridge of the nose)
- almond-shaped eyes that slant up
- a short neck, small ears
- small hands and feet
- poor muscle tone or loose joints

Most individuals with Down Syndrome experience an intellectual disability that ranges from mild to moderate, meaning that children with DS may need additional time to manifest confidence in writing, speaking or control of the body, as well as struggle in the manipulation of numbers, abstract concepts and grammar.

Other significant intellectual and behavioral struggles are:

- a generally shorter attention span
- poor judgment
- impulsive behavior
- slow learning
- delayed language and speech development
- struggles associated with mathematics and abstract thinking

Figure 1.1

According to the the WHO (World Health Organization), there are over 1 million individuals with Down Syndrome in the world, making it the most common chromosomal disorder [6] . Each year, about 6000 babies are born with DS, which is about 1 baby each 700 born. It is also relevant to observe that such number has been

[6]: Stevenson et al. (1969), 'Down's Syndrome in Families Referred for Advice'

steadily increasing over the last decades, marking an increment of 30% between the 1979 and 2003 alone [7] .

[7]: Shin et al. (2009), 'Prevalence of Down syndrome among children and adolescents in 10 regions of the United States'

Regardless of their demographic presence, people affected by Down Syndrome have had a tragic history of misunderstanding and mistreatment, being wrongly labeled because of their difficulties, and punished for their condition by being placed in institutions, or being prevented from attending public places. For the majority of the 20th century, it was considered normal that an individual with Down Syndrome would not be able to learn, write or speak, and the condition itself was considered responsible for an extremely short lifespan. It wasn't until the 1970 and 1980 that people with Down Syndrome were deemed "human" by the general public, and that efforts started being made into teaching and supporting the individuals born with it [8] .

[8]: Wright (2011), *Downs*

Today, the average lifespan of a person with Down Syndrome has increased to approximately 60 years (adversely, it used to be 25 in 1983), and many children with Down Syndrome are able to complete secondary school and, whilst less commonly, land a job in society.

Numerous organizations across the globe have risen to advocate the rights of people with Down Syndrome, and while there is no comprehensive list of all[1] , GDSD estimates the existence of at least one active organization in every first world country.

In some cases, people with Down Syndrome have been given the possibility to speak for themselves, as in United Nation events, where since 2012, 78 speakers with Down Syndrome have represented the rights and dignity the community [9] .

[9]: Li et al. (2006), 'Successful experience of people with Down syndrome'

In light of the vulnerability and pacific behavior of people with DS, it is possible to look at such events not only as a testing ground for representing the minority itself, but also as a thermometer for the values of free speech and human rights modern democracies are built upon.

1.3 Observations on Down Syndrome and Time Awareness

According to the author's personal experience, most individuals with Down Syndrome display an understanding of time that is only approximated, and while the majority of the individuals does identify past, present and future with ease, the manipulation of time units (such as minutes, hours, days) appears to be much more limited.

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[1] The closest one being the one compiled by the Global Down Syndrome Association, available at `https://www.globaldownsyndrome.org/`

Most individuals with DS display to be seeing a certain hour (ex. 16:00) as nothing more than a language label to address something frequently mentioned, and while knowing that something will occur at a given hour is generally understood (ex. Eating at 16:00), the underlying relationship between different times of the day remains often vague.

Analog and digital clocks are often taught to children with DS since Early Age, still results are often mild, and in the best cases, translate into the the ability (acquired across years to intensive teaching) to recognize and speak out hours by glancing at the clock quadrant. In the end, an ability that is mostly used to seek or guide assistance from others.

Time-related struggles determine significantly the quality of life of individuals with DS, and are the direct cause of impairments such as:

Exaggerated wait: waiting all day for an activity that will be taking place only late in the evening, guided by the feeling that it may be coming "at any time now". A feeling that cannot be eased in most cases by caretakers, and that in the long term leads to either a perpetual condition of stress or the rejection of duties.

Overindulging in activities: washing hands for more than half an hour, watching TV all day. Most commonly with repercussions on personal health (ex. bruised hands, damaged vision, ..) or fueling social isolation, also identified as a risk factor for cognitive degeneration in individuals with Down Syndrome).

Impaired decision making: inability to plan in advance, or to commit firmly and self-consciously to an undertaking - mostly resulting from the inability to understand when or for how long the commitment will play out in time. Generally causing individuals with Down Syndrome to be forced to delegate their life-planning to someone else [2] .

Limited self-awareness: such as the awareness of becoming old, or the necessity to build stability for a more difficult future. As mentioned in the opening statement, awareness of time (of its limited quantity) is a fundamental drive of human life.

In light of such observations (further verified in the thesis), it is reasonable to suppose that people with Down Syndrome may be experiencing undiagnosed Dyschronometria as an implication of the DS condition.

[2] 2: Typically family, that is indirectly affected as well.

Regardless, the author suggests that another explanation is also possible.

There is surprisingly little research regarding awareness of the passage of time for individuals with Down Syndrome, with only a publication addressing the sense of Rhythm (intact in individuals with Down Syndrome) [10, 11] and struggles associated with counting (distinctly present) to be used as comparative material.

[10]: Stratford et al. (1983), 'Rhythm and time in the perception of Down's syndrome children'
[11]: Faragher et al. (2013), *Educating Learners with Down Syndrome*

Still, according to such documentation, individuals with Down Syndrome are perfectly able to feel and quantify the passage of a moment, but struggle at describing anything when asked to do so in a mathematical, purely abstract language.

The hypothesis of the author is that individuals with Down Syndrome struggle at understanding (and discussing) time, but that such struggle has not to be attributed to the biological inability to perceive passing time (Dischronometria).

Rather, the author suggests that Time unawareness for individuals with Down Syndrome is the result of how Time is conventionally represented (numerically), a format that is likely to be very difficult to understand for individuals of the minority.

1.4 Aim of the thesis

The objective of the following thesis is to redesign what a clock is (i.e. how it communicates time) according to the needs of an audience that is not able to understand mathematics or abstract thinking - in this case, specifically for individuals with Down Syndrome.

Conventionally, digital time is represented in a format that is minimal (uses barely four digits), abstract (relies entirely on the user's ability hold constructs in memory), unappealing (does not ask for attention, nor puts emphasis on its meaning) and impersonal (does not refer to the living context, nor to its user).

The objective of the following thesis is to design an interface where time is represented explicitly (using sounds, images and animations), physically (draws from material interactions and elements of the real world) and contextually (referring actively to the user's personal life and identity).

The solution will manifest as a prototype of a mobile app where time is represented as a visual metaphor (visual learning is strong in individuals with Down Syndrome), and the overall passage of a day is experienced by the user as an illustrated journey, rather than mathematical information.

For example, while a digital clock would display 4 digits (ex. "11:40"), the interface would represent a character (representing the person) that undertakes a journey towards lunch, dinner, bedtime, and a path that connects such events. Within such system, the character's position would reflect current time.

In other terms, the application will represent time as a spatial metaphor, and progressing time as visual changes on a clear and measurable track.

Using the application (Tempo) users will be able to pinpoint (rather than calculate) where the living moment is in time, how distant (in time) an upcoming event is, how much free time there is left in a day, and when.

1.5 Implications

If successful, the implications of a similar study will be many, and hardly possible to trace out in this thesis alone.

The existence of a device that enables time manipulation for individuals who are currently prevented from it might revamp the discussion on the factual definition Dyschronometria (inability to perceive time), which as anticipated in the previous sections, is already controversial and difficult to determine [3] .

Concerning individuals with Down Syndrome, success (making of a clock understood that is understood) would prove that the inability to manipulate time is not congenital (Dyschronometria), but rather, the result of ineffective, inaccessible designs available until this moment.

Lastly, it is likely that, in case of success, the resulting design should be tested with a broader audience, also involving individuals from conditions such as Dementia, Alzheimer, Discalculia, Autism and children at developmental age.

[3] It should be noted, in this regard, that Time perception has not been attributed to a precise area of brain, and according to "", has to be considered a combined effort of emotional, mnemonic, mathematical and spatial intelligence, leaving margin for experiments as the one described by the following thesis.

Establishing Design language for Down Syndrome

2

2.1 Design around specific strengths

Although every person with Down Syndrome is a unique individual, some relative strengths and weaknesses appear to be shared across many, mostly as a result of the physical and intellectual traits from the condition.

Just as the weaknesses stand at the source of most of the limits in the lives and opportunities of people with DS, strengths represent a force to balance them out, allowing designs and solutions that rely on solid skillsets and exploit affinities to create the illusion of simplicity.

The following chapter will offer reflections (marked in blue) based on the developmental profile of Individuals with Down Syndrome, described by the Down Syndrome Education International (DSEI) and Down Syndrome Intenational (NSI) as the fingerprint of the most relevant traits associated with the condition [12, 13] .

[12]: Kim et al. (2017), 'Motor and Cognitive Developmental Profiles in Children With Down Syndrome'
[13]: Carmeli et al. (2012), 'Movement skills of younger versus older adults with and without Down syndrome'

Learning these traits (as well as their origin) early in time has been a necessary step of developing a design language for individuals with Down Syndrome, easing decision making for any following stage of design.

2.2 Weaknesses of people with DS

Delayed motor skills

Most children with Down Syndrome develop gross and fine motor skills[1] at a slower rate, translating into a more impaired functional performance, coordination, and leg muscle strength.

For the design of an interface, it means that it will be more likely for accidental or inaccurate inputs to be provided, meaning that interactive areas (as might be touch-sensitive areas) and error tolerance should be adjusted accordingly.

[1] Gross motor skills pertain to skills involving large muscle movement, such as sitting, crawling, walking or running. Fine motor skills refer to skills involving smaller muscles, such as grasping, object manipulation or drawing.

Hearing and Vision

Hearing and vision are also affected. It is common for many children with Down Syndrome to have restricted ear canal, such difference often translates into frequent inflammations, that if mistreated, lead to chronical or permanent hearing loss. Having a restricted hearing canal also accounts for what is called Conductive Loss, meaning that wax accumulation in the conductive canal is directly responsible for deafening. Such vulnerabilities are vastly shared across people with Down Syndrome, and result in about 80% of the community having mild to severe issues with hearing.

Vision is also a frequently impaired sense. According to the study "Vision Deficits in Adults with Down Syndrome" by Sharon J. Krinsky, Wayne Silverman [..], most adults with Down Syndrome experience significant vision deficits, with a pattern similar to the one observed in adults with Alzheimer's disease. About 50% of people with Down Syndrome need to wear glasses, and 100% of people with Down Syndrome have poorer visual acuity that their contemporaries [14] .

As explored in the chapter [] this is not the only case where individuals with Down Syndrome seem to experience conditions typical of early aging, such as Alzheimer, and while such similarities do raise concerns on one side, on the other it means that successful design approaches (and not only) might be possible to be carried over from one research field (Alzheimer) to the other (Down's Syndrome).

Visual struggles can also be very specific. According Lavinia Postolache in "Abnormalities of the Optic Nerve in Down Syndrome and Associations With Visual Acuity", most individuals with Down Syndrome may find it more difficult to identify fine details and perceive sharp contrasts, mostly due to a lack of sensitivity in the eye, suggesting the use of big, clear fonts and bold line thickness to be a viable choice when printing or displaying text for children or adults with DS [15] .

It is clear that design-wise such recommendations are no less valuable, and that a general direction of bigger, easier-to-be-detected visual elements must be preferred at stage of prototyping.

An interface designed purposefully for users with Down Syndrome will take into account such difficulties, and make sure to not make exclusive reliance on either one sense or the other. A good strategy in these cases is usually to take a multi-sensorial approach, and deliver the message (output) across as many sensorial inputs as it is possible (and meaningful) to do. It is also important to consider that a message which relies on multiple senses to be delivered (as an on-screen message, followed by a sound and perhaps a vibration)

[14]: Krinsky-McHale et al. (2014), 'Vision deficits in adults with Down syndrome'

[15]: Postolache (2019), 'Abnormalities of the Optic Nerve in Down Syndrome and Associations With Visual Acuity'

should not aim at being completed by the simultaneous presence of all sensorial inputs (as it is reasonable to do in multi-sensorial entertainment), but should instead include a degree of redundancy on each one, making possible for a user with partially impaired senses to reconstruct the message regardless of what is missing.

Hearing and Language

Most children with Down Syndrome learn how to speak at later age, and keep struggling with grammar, tenses and word endings throughout their lifetime.

In "Language in Adults with Down Syndrome" (Annick Complain and Jean Adolphe) suggest language to be the most affected area of development by Down Syndrome, due to sentence formulation, comprehension, as well as articulatory and phonological skills all being affected by the condition.

Most individuals with Down Syndrome exert a speech characterized by short utterance, a limited range of vocabulary, immature syntax, as well as a distinct struggle at storing and processing sentences. Such difficulties fall under the spectrum of Verbal Short-term Memory.

Dysarthria (i.e. breakdown in the ability to control mouth and lips muscles for speaking) and Dyspraxia (i.e. breakdown in the ability to select, plan and sequence which speech sounds to use) are also very common, as it is stuttering (although there are signs for it to be caused by mismanaged social pressure) [16] .

As design becomes of concern, such difficulties will affect deeply how information are both presented to and expected from the user, pushing forward solutions that don't rely on complex sentencing, exceedingly long action sequences, memorization or precise voice command for success.

Math skills

The majority of children and adults with DS struggles with basic mathematics, and such difficulties include counting (representing numerical quantities in their mind), comparing (discriminating between quantities), and arithmetic calculations. Yet, such struggles are not easily compared with the skillset of an infant, or child, and are instead characterized by specific weaknesses, mostly attributable to the broader clinical picture. "Enumeration skills in Down Syndrome" (Francesco Sella, Silvia Lanfranchi and Marco Zorzi) is an excellent resource, and portrays a very complete investigation on the mathematical underachievements of individuals

[16]: Chapman et al. (2001), 'Language, cognition, and short-term memory in individuals with Down syndrome'

with DS. It is observed in the paper how the extimation (approximate counting) of small numerosities appears to be much more challenging for children and adults with DS than the extimation of bigger numerosities. In other words, as the number of elements making a set increases, it becomes much easier, for a person with DS, to tell how little or how much a quantity is [17] .

[17]: Sella et al. (2013), 'Enumeration skills in Down syndrome'

A possible explanation (reflection of the author)

A possible explanation could be that as quantities becomes bigger, learning becomes more visual, and people with Down Syndrome are able to draw from one of their strongpoints, Visual Learning. If that were to be verified, it would mean that the readability of quantities for people with Down Syndrome would not only be determined by the (sizeable) numerosity of the evaluated set, but also (if not mostly) by the way elements in such set are arranged, and how well such arranging communicates numerosity itself. Moreso, as quantities turn into sizes, enumeration becomes more instinctive, less reliant on memory, further reducing the impact of Verbal Short-Term Memory (previously cited weak point) on the counting process.

But defining the struggles is not enough. In fact, given the extreme prominence of mathematics in everydays lives (time, monetary value, geolocalities, and more are all expressed with numbers), lots of efforts have been done to support the learning of mathematics for people with Down Syndrome, and must be noted that, regardless of initial difficulties, the majority of educated individuals reaches adulthood with the ability to count up to double digits and complete most basilar operations, such as additions and subtractions.

While very detailed, such exploration will be essential at design stage, affecting how numbers, as well as sequences and quantities (which account for the majority of displayed information) will be (meaningfully) displayed. Time itself, whom communication is at the forefront of this design effort, is indeed a (Scalar) quantity.

2.3 Relative strengths of people with DS

Visual Learning

Most people with Down Syndrome are visual learners, and find themselves at ease if a concept is presented to them as an illustration rather than textually. This finding has been demonstrated across various areas of development, including language, motor skills and literacy, where information presented with the support of pictures, but also using gestures or objects, were far more successful at teaching [18] .

For design, such principles are easily adapted, by using visuals clues (v/s text), requiring frequent physical interactions (v/s minimalist interactions) and by letting interaction unroll before the user's eyes (v/s telling the user how to do it[2]).

Social understanding, Empathy, Social skills

Regardless of their struggles with speech and language, the majority of people with Down Syndrome is keen to communication, closely empathetic, and able to tell a good behavior from a bad one. Children are seen enjoying and looking for eye-to-eye contact since early months of life, and most individuals show no effort at picking up non-verbal clues, including facial expressions, tones of voice and body postures [19] .

Once again, this is an example of "native language" that appears to be easier for the users, and that (like Visual Language) should be preferred when communicating over an interface. Relevantly, such languages should not be restricted from being mixed, allowing (for example) a solution that employs an illustration (Visual Representation) of an upset character (Social Sensitivity) to convey a message. Likewise, the use of character, combined with a user base that is able to understand body language, would allow for characters that communicate the urgency (Social Sensitivity) of an action (Visual Representation) as it is displayed to be taken. While not repeated in the following paragraphs, such approach is proper and could be reasonably applied with any combination of languages.

Visual Short-Term Memory

Lastly, most people with Down Syndrome demonstrate sound visuospatial[3] Short-Term Memory (as opposed to a weakened Verbal Short-Term Memory), leading to efficient orientation and navigation of environments (as well as a strong potential for indipendency in everyday living) [11] .

Words and images in memory

Verbal and Visuospatial Short Term Memory are frequently mentioned along in studies of neurological disorders and cognitive developments. This is due to such cognitive areas being

[18]: Iglesia et al. (2005), 'Prose learning in children and adults with Down syndrome'

2: "Show don't tell" is also a well-renowned narrative technique of Anglo-Saxon derivation, a mantra that started as a recommendation for writers, and over time has translated just as efficiently across cinema, design, marketing and more.

[19]: Valdívia Lucisano et al. (2013), 'Skills and social interaction of children with Down's syndrome in regular education'

3: Referring to both Vision and Space.

[11]: Faragher et al. (2013), *Educating Learners with Down Syndrome*

central of what is referred to as Working Memory, namely, a segment of memory that stagnates for short periods of time, as is tightly related to decision-making and reasoning - one could think of it as the "cache" in human brain.

Design being of concern, knowing how skilled the user base is at retaining visual information, and at navigating environments, is easily central. Users that are able to read and memorize more complex visual paths will be suitable for a deeper navigation (for example, will be allowed to trace themselves while performing an operation that "jumps" across several screens), as well as tollerate more cluttered visuals (eventually serving more complex purposes).

Evaluating existing time-telling solutions

3

3.1 Evaluation criteria

The following chapter will explore any eligible candidate that could possibly work as a time-telling device understood by individuals with Down Syndrome.
Devices developed across history and present times are taken into consideration, as well as any published research paper addressing such need.

While many existing solutions, such as clocks (time telling devices), are substantially ancient, the evaluation criteria(s) that will be used by this study to asses their validity are modern.
The choice is deliberate, as most modern design methodologies have a philosophy of designing around the specific requirements of the user (User-Centered Design), as opposed to older approaches that focus on the efficacy of the tool (Machine-Centered Design), and expect users who are able to learn how to use it.

A real-life example

Such difference can be easility found in how personal computers have changed over the last 40 years, moving from expert-only limited devices to almost all-around accessible devices.

User Experience Evaluation (UX Evaluation) is a branch of User-Experience Design (UX Design) that focuses on the evaluation of existing systems in light of modern design priorities, supporting both expert and novice designers with a set of core values for design efficacy [20] , such as:

1. Utility: Does the user perceive the functions in the system as useful and fit for the purpose?
2. Usability: Does the user feel that it is easy and efficient to get things done with the system?
3. Aesthetics: Does the user see the system as visually attractive? Does it feel pleasurable in hand?
4. Identification: Can I identify myself with the product? Do I look good when using it?
5. Stimulation: Does the system give me inspiration? Or wow experiences?

[20]: Väänänen et al. (2008), 'Towards Practical User Experience Evaluation Methods'

6. Value: Is the system important to me? What is its value for me?

Interestingly, it is already possible to see how modern clock design disregards or violate some of these core principles, further suggesting why a solution that values the needs of people with DS is not found in such time-telling devices.

3.2 Existing solutions in history

Time is essential for the life of humans, as such, countless solutions have been invented over human history as a mean to tell the passage of time. Some examples are Candle clocks (AD 520), Incense clocks (AD 960), Sundials (AD 1371), Hourglasses (AD 1338), Clocks with gears and Astronomical clocks, all of which rely in the projection of light or the use of reference points to address time itself. By looking at [Time-Telling Devices] (Robert Hannah) and [A chronicle of Time-Keeping] (William J. H. Andrewes) [21, 22] it appears confirmed how most devices rely on mathematics and abstract thinking for their function, yet there are some interesting observations to be made.

[21]: Hannah (2016), 'Time-Telling Devices'
[22]: Andrewes (2002), 'A Chronicle of Timekeeping'

- Restricted to what is possible to be seen -
All of existing devices are exclusively visual: there appears to be no reliance on other senses. Most likely, as sound reproducing devices are a relatively new invention (Phonograph cylinder, Thomas Edison, 1878) and came after analog clock had already enstabilished themselves in a position of power. Lastly, Design for Accessibility (or Design for those who are weaker) was only vaguely addressed until recent times.

- Newer devices relied more on math and abstract thinking -
Interestingly, the more advanced (and precise) the tools became, the less they started relying (even) on visuals, moving towards an essentialism based on mathematics and abstract thinking, - which responds to a lethal combination for people with DS.

In fact, while highly imprecise, and not of realistic use in a modern context, older methods were significantly more friendly to users with Down Syndrome than modern tools are - relying on visual inputs such a seeing a shadow as it was casted around a pole or looking at a candle as it consumed throughout the night, far from cardinalities, numbers or time units fragmentation.

While not Usable (2), Personal (3) or Exciting (5), such solutions will indeed provide a ground to reflect at the moment of building a modern, comprehensive design.

3.3 Existing solutions today

While it is tempting to limit the exploration to the extent of only actual clocks, it is also relevant to observe how in modern, digital times, clocks are not the only way time and duties are being kept track of and displayed. In fact, there are plenty of applications working as calendars, fitness trackers, diet assistants, note-takers, Gantt apps and more that, whilst still tied to a numerical labeling of time, provide additional visual clues on how time could be organized, marking a timid, yet significant departure from abstract-only digital watches.

As part of an effort of preliminary research, the author has scouted over 50 different applications across Windows, Mac, mobile and Web-based systems, and produced a representative set of three apps, which are amongst the most visual-reliant, text-minimal examples that could possibly work as time-telling devices for people with DS.

- SplenDO, To Do List for Android - by SplendApps
- Project Time Tracking - by RepliCon
- Mobile Time Tracking OG - by Timesheet

Representing respectively three possible souls of time tracking apps: (i) desktop, excel-like visual structure for appointments, (ii) mobile, appointment-based app, (iii) mobile, to-do list app.

These services are excellent at keeping track of duties, appointments, and at presenting such obligations in a structured, meaningful way. Yet, quite expectedly, these are also tools made for professionals and experts users, and will become mostly inadequate if tasked with communicating time awareness to people with DS. Concerning our very specific use-case - using these tools as a way to enhance time-awareness in people with DS - the following points of struggle have been identified:

- Absence of visual clues on time flowing -

The constant, progressive nature of time is never addressed. Events and duties are displayed and removed as time passes, but no clue is given on the continuous passage of hours, minutes, seconds (as it happens with the use an hourglass, for example).

- Formal language -
Language is often not accessible, and makes wide use of advanced terms (such as Budgeting, Rates, Analytics, Statistics,..) that can be easily seen as harder to understand for users with DS.

- Cluttered visuals -
Interfaces are bloated with text and numbers, making visual navigation very difficult for users with impaired cognition.

- Reliance on the user's very own mental organization -
All of these apps do very little when it comes to organizing and segmenting time for a user who doesn't understand it, in fact, most of what is displayed on screen has been previously arranged by the user alone.

- No sign of actual adoption -
While not implicitly a proof of fault, these kind of applications have existed for decades. Yet, no sign of adoption seem to have sparkled in cooperatives or institutions that take care of people with Down Syndrome. Since technology appears to be widely appreciated and used by the Down Syndrome community, such results could be taken as a confirmation that a similar solution is in fact needed, but not present yet.

Lastly, it is possible to see how most of these criticisms can also be read as violations of UX Evaluation criterias, such as Usability (2), Aestetics (3), Personality (4), Excitement (5) or Clear value (6).

3.4 Existing research

Previous sections have introduced the presence of manifest time-related struggles in individuals with Down Syndrome (further validated in the thesis), and commented on how such struggles could be easily related to the specific limitations that come with the condition, such as the conceiving of mathematical or abstract concepts (valuable research topic).

Yet, there appears to be no existing research paper or institution that addresses the problem directly.

For the means of this study, the author has sought for any possible connection with the topic, exploring the databases of Google Scholar, Microsoft Academics, BASE, CORE and Science.gov search engines, yet the closest match appeared to be:

(i) Aging discrepancies in individuals with Down Syndrome (most people with DS display early aging symphtoms).
(ii) The affinity of people with DS with Music and Rhythm (that according to the study appears unaffected by the condition).
(iii) Difficulty at holding long sequences in memory (as it happens in counting, where we unconsciously "hold" the quantity we are thinking of in our head, ex. 12 is not pictured as a single unit in our head, but as many).

While all of such resources [10, 17, 23] possible to be traced back to how people with Down Syndrome perceive time - such as with memory number sequences (iii) (used in clocks and traditional time description) or basic rhythm (ii) (used to assess the instinctual perception of time units, and guess the passage of seconds, minutes, hours) - no efforts appear to have ever gone in the direction of discussing (either for confirming or dismantling) the specific struggle of Time Awareness.

[23]: Esbensen et al. (2016), 'Differentiating Aging among Adults with Down Syndrome and Comorbid Dementia or Psychopathology'
[10]: Stratford et al. (1983), 'Rhythm and time in the perception of Down's syndrome children'
[17]: Sella et al. (2013), 'Enumeration skills in Down syndrome'

Methods 4

4.1 Type of study

The study is possible to be identified as a Creative Qualitative Study adapting the Grounded Theory Methods.

A Qualitative study* is a study based on gathering non-numerical data (such as text, video or audio) and using such data to understand concepts, opinions or experiences.
Qualitative studies are generally used to produce in-sights on a specific topic, or to generate new ideas for research.

For the means of this project, the objective was to generate insights and guidelines for the creation of a time visualizer for people with Down Syndrome, making of such process the most adequate choice.

The Grounded Theory (GT) is a Research methodology that asks theories to be laid on top of previously gathered information, making field research always come first in the process.

Inspired by the "Interpretative Paradigm" (i.e. researching and identifying the underlying processes of a given phenomenon) GT has been Introduced by Glaser and Strauss (1967) as a way to legitimize Qualitative Studies, and remains to this day one of the most respectable frameworks concerning design research [24] .

[24]: Glaser et al. (2009), *The discovery of grounded theory*

4.2 Design milestones (map of content)

The complete design process for the project took place over a time span of 9 months, and is possible to be understood according to the following milestones, loosely adapting Stanford Design framework and IBM design loop (frameworks for structuring the design process, from idea to working product). Each phase represents a milestone exhausted in the past year 2020/2021. All milestones have been preemptive for the completion of the project itself.
At the time of writing, all milestones have been completed, all data have been collected, and are anonymously maintained in a safe drive. Results, as well as auxiliary details, are found later in the thesis (Chapter 5).

Observation, July 2020
The author is inspired to work on the project by observing a close relative with Down Syndrome who struggles with time perception. Talking with friends and social operators, the problem appears to be widespread and poorly addressed by existing solutions (time-telling devices such as clocks).

Analysis of existing research, August 2020
The author undertakes theoretical investigations of the topic, learning best practices for dealing with the needs of people with Down Syndrome and more. Specific struggles from people with Down Syndrome related to time perception seem to not be mentioned anywhere. The struggle itself needs to be further validated.

Validation of the problem, September 2020
The author undertakes 15 rounds of interviews with caretakers experienced in working with people with Down Syndrome, the objective being to learn more on the relationship between people with DS and Time, as well as validating the very existence of time awareness issues in indivuals with DS. In the end, time related issues, the severity of implications and the insufficiency of existing solutions are all strongly confirmed by Experts. Focus shifts on the making of a solution.

User Research - Caretakers, October 2020
First round of interviews targeted towards learning needs and values of users with Down Syndrome. A total of 15 expert caretakers of individuals with Down Syndrome are interviewed in separate sessions. Results provide a list of extremely valuable insights, later to be restructured in guidelines for the design of prototypes.

User Research - Individuals with Down Syndrome, October 2020
Second round of interviews. In this case, 5 individuals with Down Syndrome are interviewed first-hand. 5 accurately crafted questions are asked in each round. Data are collected as answers, as well as observing emerging behavioral patterns displayed by interviewees. Once again, results are structure in sight of a more thorough analysis that will follow.

Synthesis of User Needs and Design Guidelines, November 2020
All content produced from previous interviews, all outputs from research and comments collected to this points are restructured in a set of usability guidelines purposefully made for designers who will deal with design for people with Down Syndrome, in the

future. The same guidelines will also be used the project, from this moment on.

Sketching, Conceptualization and Wireframing, November 2020
Ideas, concepts and extremes viable for the project must be tested in anticipation of practical prototyping. This step consisted in the making of over 100 sketches, ranging from character design, to the logic and mechanics with which time is possible to be represented. Only a small number of elements from this stage is brought over to actual prototyping. Testing deeply a range of viable options has allowed prototypes that followed to be more stable, and focus only on the most relevant challenges.

Prototyping & User Testing, December 2020 to April 2021
Over the course of three iterations, multiple Hi-Fidelity prototypes of an Android app representing time visually for people with Down Syndrome are designed and tested. Each interation started with a novel set of prototypes being produced, and ended with such prototypes being put to test along with users with Down Syndrome. At the end of the third iteration, one specific prototype seems to be successful under any testing ground.

User Interface Design, December 2020 to April 2021
All prototypes must also be refined visually. This is done not only for marketing purposes (curated appearance recalls trustability), but also to empower engagement, and regard users with special visual needs, such as Dyslexia, Reading impairments or weaker vision. Refinements include color calibration for colorblind people, as well as adjusted typography and visual hiearachy (visual prominence of core elements). Resulting screens become more visually consistent, virtually ready for development.

It is possible to observe how Personas have not been included as part of the design process. The decision was intentional, and motivated as it follows:

i) Personas are meant to reassure and involve stakeholders, who may not be able to see the potential customer and the reason behind design choices. Being this a research project (rather than industry project), focus was on producing documentation rather than marketing and/or internal communication.

ii) Personas are generally used for project management in agencies with group sizes of 5+ people. This project has been handled by the author alone. There seems to be an increasing number of voices which is critical towards the use of Personas in design. In regard of this project alone, it is reasonable to that using them would have resulted in unnecessary workload - likely coming at the expense of the project quality.

Another detail to be found, is that interviews involved not only people with Down Syndrome, but also Caretakers in wide presence. There are several reasons behind this choice, above all, the following ones:

i) As anticipated in previous chapters, most people with DS live in a status of only partial independence. As a result of such context, parenting figures, such as caretakers, end up being key roles at any time, affecting, influencing and being part of the life of a person with DS at any level. Accordingly, it was inevitable for an accurate study to include such roles as well.

ii) People with Down Syndrome struggle with sentencing and expressing themselves as a congenital* issues, thus, it was necessary to include an external observer who could compensate such difficulty.

iii) While being the first who benefit from the project, people with Down Syndrome may not understand the reason behind the project – and rightfully - might not be willing to contribute at all. In worst cases, basing the study solely on people with Down Syndrome might have resulted in a complete lack of participants.

Lastly, all efforts of interviewing have been pursued in respect of NSD (Norwegian Center for Research Data) regulations[1] .
At all instances, interviewees have been asked to agree on a standardized declaration of use, maintenance and recording of their data.
There were instances, such as with interviews of people with Down Syndrome, where interviewees could not personally agree to their rights - in such cases, a caretaker agreed in their stead, and overlooked the interview for its entire duration. At all times, participants have been offered the possibility to retreat, to see what information were being gathered, and to ask for deletion of any gathered content. Consent was always asked to all parties.

4.3 Observation

The project begins as the author witnesses family members with Down Syndrome who struggle with time perception on a daily basis, and feels compelled to investigate for a solution.

In particular, the author notices how health cooperatives spend a noticeable amount of time trying to teach digital clocks reading

[1] Official NSD website `https://www.nsd.no/en/`

to people with DS, despite such tools being extremely unfriendly (cognitively-wise) to the DS community.

Much like computers became accessible only recently for many people, thanks to the arrival of modern smartphone era - and the implementation of modern accessibility principles - the author wonders if it is proper time to rework time presentation as well, and make it more inclusive for all those who need it.

Early confrontation with friends and health cooperative leaders seemed to address that such solution was needed, possible and absent. Yet at this stage, further study was required.

4.4 Analysis of existing research

Researching documentation consisted of a deep, thorough exploration of any content concerning users, context and feasibility for the project.

Among elements that became part of this investigation, are a formal analysis of the Down Syndrome spectrum (brought to this thesis in earlier chapters), a study design principles for inclusivity, of teaching practices for children with Down Syndrome, of teaching for individuals with Alzheimer (which shares many defining traits with Down Syndrome [25]) and more. Material came from scientific articles (generally probed with -), but also from books of various genres (design, medicine, teaching) or trusted web publications[2] .

Concerning the specific topic of time perception from people with Down Syndrome, should be noted that results ended up being encouragingly shallow, leading to problem validation in phase 3. If on one side very little documentation may be suggestive of an undiscovered, neglected challenge, on the other it means that verifying that the verifying that the problem does indeed exist will be among the duties of the research.

4.5 Problem validation

Trustability stands at the forefront of every project, as it is to demonstrate that an actual, existing problem is being targeted - otherwise, it is easy to fall for personal biases, or believe in positive results from poor pooling practices.

Up to this point, the relationship between Down Syndrome and Time, it's implications, and the inadequacy of existing solutions

[25]: Schachter et al. (2000), 'Alzheimer's disease'

[2] Unreliable information was at all times traced back to the (generally trustable) original sources, or simply left out of the study.

(digital / analog clocks) were mostly based on the author's personal experience and informal reports from acquaintances.

Theoretical research (phase 2) supported the existence of the issue (the clinical picture for Down Syndrome has a strong affinity with time related issues), yet the problem itself (people with Down Syndrome struggling with time perception) was never addressed outrightly.

Prior to any further advancement with the project, a Study of Feasibility (Problem validation) was necessary to be taken. Problem validation consisted of performing a set of interviews with experts of DS, specifically, with the intention of proof testing the following arguments:

1. People with DS having an actual struggle with time perception, specifically as it expressed in seconds, minutes, hours and days.
2. If present, whether such struggle does have active and severe implication of the quality of life (ex. Source of stress of loss of independence).
3. How proficient people with Down Syndrome appear to be in the use of clocks or any other time-telling tool. What could be done to improve these tools.
4. If the project itself appears to be a reasonable and justified effort.

A total of 15 experts have participated in the interviews, including:

- 4 Psychologists (who actively follow individuals with DS in therapy)
- 2 Health Cooperative Leaders (who manage groups also including members with DS, and are experienced in organizing events that comply with special needs)
- 9 Caretakers (including art teachers, language teaches, entertainers and clinic caretakers)

Questions have been asked for approx. 2 hours each on Zoom [3] in separate sessions.
Only note taking has been used for data collection. According to the qualitative nature of the study, interviewees have been encouraged to provide any kind of feedback – including impressions, opinions and stories of past experiences – at all instances, it has been made

[3] Remote video-calling platform, official website at `https://zoom.us/`

clear that any answer would contribute in enhancing the quality of the project.

Follows the list of asked questions:

1. Could you describe your job?
2. For how long have you been doing it?
3. How are people with Down Syndrome involved in you work, and how much experience do you have with people with Down Syndrome?
4. How would describe the relationship with Time of the people with Down Syndrome you were able to caretake?
5. How was their relationship / use in regard of the concept of seconds, minutes, hours?
6. How skilled were they in the use of analog or digital clocks?
7. And at planning daily, weekly or monthly commitments? How often, and how efficiently were such commitments met?
8. Have you ever seen them [caretaken people with Down Syndrome] in a situation of hurry, emergency or pressure? If yes, of did they respond?[4]
9. If ever existed a mobile app that showed them time as something graphical, using their daily commitments as references for example, do you think it would be useful in any way? Or do you think it is not really needed?

Interviews took place in the city of Rome, Italy (mostly due to practical restrictions accountable to the pandemic).
All interviews have been handled in Italian and translated for this study. Relevantly, opinions and suggested social approaches might be very well influenced by cultural and social factors – still, there is no reason to believe that the actual results of the study, a clock for people with Down Syndrome, would not be applicable elsewhere (Down Syndrome manifests itself with the same characteristics regardless of region).

Results, especially in regard of the concept for an alternative clock, were extremely positive, and the problem of time telling itself was confirmed in almost all interviews.

[4] Time awareness may introduce an additional stress factor, thus it is relevant to explore in this direction as well.

4.6 User Research - Caretakers

Need Finding is the process of researching what is important (values) and needed (requirements) by the user, and is an essential step in the design of any product.

Upon confirmation that the project was both needed and possible, the following step focused on learning anything about the habits and the requirements of individuals with Down Syndrome.

For the study, Need Finding consisted mostly of scripted interviews with selected pools of users.

Other than insights on the behavior, shared traits and needs of individuals with Down Syndrome, Questions tried to gather specific tips based on the lifelong experience of interviewees at teaching, for example asking how they find themselves explaining particularly difficult concepts, both written and verbally.

Also in this case, a total of 15 experts have been involved in the effort, pooled as it follows:

- 2 Psychologists (who actively follow individuals with DS in therapy)
- 5 Health Cooperative Leaders (who manage groups also including members with DS, and are experienced in organizing events that comply with special needs)
- 8 Caretakers (including art teachers, language teaches, entertainers and clinic caretakers)

Interviews took place in the city of Rome, Italy, and have been handled in Italian. Also in this case, content has been eventually translated for clarity in the thesis. Data have been gathered by note-taking throughout the process.

18 questions have been asked in total. Across all questions, arguments are possible to be subdivided among the following types:

(i) profiling questions – which aimed at assessing the source for provided information.

(ii) users – aimed at learning about habits, shared behaviors and needs.

(iii) critical challenges - learning about specific struggles that need aid.

(iv) technology - about the relationship of technology and existing solutions.

Follows the complete list of questions in clear:

1. What is your job? For how long have you been doing it?
2. What does your work usually consist of?
3. Can you tell any way working with a person with DS is different from working with other people you've been assisting?
4. Can you identify any distinctive needs people with DS seem to have?
5. On an average day, what would you expect to be the daily routine of most of the people with DS you follow? Are there any activities that seem to be more popular than others?
6. What do you think is in the thoughts of the people with DS you follow of the time? Is there something they seem to care the most about?
7. How possible do you think it is for a person with DS to be independent? If yes, to what extent?
8. How common are physical struggles? Do you ever witness difficulties related to that? Re: Such as at walking, writing, using a keyboard - anything that concerns controlling one's body.
9. And psychological struggles? Does anything come to your mind?
10. What is the approach you take when you need to present or explain a concept to a person with Down Syndrome? Re: Try visualizing it in your mind: is there something, anything that you find yourself doing when you need a message to "get through"?
11. Accordingly, do you find yourself following certain attentions when presenting a concept graphically (on paper)?
12. And verbally?
13. Have you ever found yourself thinking that one of the people with DS you follow would not have managed to do something, and then he/she surprised you? If yes, could you narrate the episode?

14. If you could appear out of thin air, and be there to help one of the people [with DS] you follow at a given moment of the day - which moment would you choose?

15. If you could choose a single concept (either cognitive or visual) and make it clear forever in the minds of people with DS you follow, what would you choose?

16. What relationship do people with DS you follow have with technology, specifically with smartphones?

17. Can you think of any application that appears to be particularly popular? Why do you think it is so?

    Being a Qualitative Study, there were some instances were questions accounted for more than eighteen. Such was the case of when personal experiences were presented by the interviewee, and asking for more details on the resolution of a specific situation would lead to interesting insights.
    This first session of Interviews brought major contributions to the reasoning for the project, affecting majorly decision making that took place at later stages of the process.

4.7 User Research - Individuals with Down Syndrome

Interviews also took place for people with Down Syndrome, still, the process had to be adjusted to the specific needs of communication of the minority.

As introducted in chapter 4.2.1 people with Down Syndrome suffer from attention deficit, and find more difficult to hold long and complex sentences in memory. Scripting questions for interiviewees with such difficulties meant trying to work around such difficulties, and find alternative ways to generate insights from the interviewing process.

Accordingly, it can be seen how questions at this stage have been crafted in way to provoke rather than ask for aswers. At the moment of asking, questions have been repeated if necessary. The delivery of each question has been handled in a playful manner, and utmost care has been given to understand whether a topic could be putting the interviewee at unease.

Another factor which demanded particular attention was the attitude of some interviewees at providing misleading cues, or not sincere answers. This is very common when interviewing people with Down Syndrome, but nontheless often overlooked. As presented in chapter 5.23.2 , individuals with DS tend to display a brilliant social awareness, but not as clear priorities – as a result, answers are in some cases provided as a way to satisfy the interlocutor, rather than providing a feedback.

For this exploration, focus has gone into exploring everyday habits, stress patterns and more on the relationship with technology of users with Down Syndrome.

According to the cognitive profile of people with DS, each question has been crafted to feel minimal (easier to hold in memory), personal (entertaining and relatable for the interivewee) and based on daily context (i.e. easier to recall and describe).

For this effort, a total of 5 individuals with Down Syndrome has been interviewed.
Each interview took place as a WhatsApp videocall, and lasted circa 40mins. (on average).
Each interview consisted of 5 questions, repeated or reformulated if necessary.

List of used questions in clear:

1. What is the most important thing in the day, for you? [Aims at learning habits, values.]

2. What do your parents always ask you, that you don't want to do? [Stress factors, critical duties, why some duties are refused, relevancy of family]

3. What do you do with your phone? [Relationship with technology, existing accessible apps to learn from, how apps are interacted with, what does get more attention of existing apps]

4. What is your favorite movie? Why? [Most effective communication, value, retention of long term verbal and visual concepts.]

5. What time is it now? What does it mean? / What will you do after this call? And then? [Asking users to describe time with their own words, build on top of how time is already perceived, described and visualized]

Similarly to previous efforts, interviews took place in the city of Rome, Italy, and have been handled in Italian.

Lastly, it is relevant to observe how, in light of the specific class of users, most valuable insights did not come from what was answered during interviews, but rather, from how answers were provided. Such analysis, which accounts for the most valuable insights gathered, took place observing non-verbal clues as the following:

Understanding
How well were posed questions understood - affecting communication at further stages of design.

Speaking
How answers were grammatically formulated - contributing to the making of a familiar language that will mimic the one adopted by users.

Response time(s)
Which was the overall response time to a given answer - affecting animations and interactions in design.

Emotional triggers
What was the emotional response to given topics - such as annoyance, interest, enthusiasm, alienation - affecting visual themes and language at later stages.

Body language
What reactions in body language were triggered by offered questions and topics.

Most of which are measurable and compatible with the formality of a research study.

4.8 Synthesis of User Needs and Design Guidelines

Upon completion of the interviewing effort, all gathered data have been cleansed of redundancies and condensed in two separate sets of insights for design:

1. **User Needs**
   Representing what is important for the people with Down Syndrome concerned by the study. Examples are Social inclusivity (feeling “part of the community”, doing what everyone

do) or Feel encouraged (not unlike children, people with Down Syndrome may feel unsure, and tend to show great appreciation for being loved and taken care of), Having a structured list of values allowed to asses priorities in design with more clarity. One clear example is the decision at later design stages to label moments as they are named in conventional time description (ex. "08:00"). The app will describe time visually, and "08:00" might be very well described as "Start" – yet, Social inclusivity tells us how important is for a person with Down Syndrome to - not only understand time – talk of it as anyone else could. This knowledge will translate in the ability (for the user with Down Syndrome) to not only know what time it is, but also answer someone who is asking "what time it is", providing participation and fueling a sense of community.

2. **Design Guidelines**
   Representing a set of recommendations for tuning design according to the limits and characterizing traits of a userbase of people with Down Syndrome. Usability guidelines may target a specific group of users (ex. colorblind people) or a specific technology (ex. VR), given the complete absence of design recommendation for people with Down Syndrome, it has been decided to make of a set of design guidelines especially for people with DS one the contributions from this thesis. These guidelines are assimilable to a traditional set of usability guidelines (ex. Nielsen Normann Heuristics), and provide assistance to the designer for detecting well-known pitfalls, introducing relevant features and generally, make for a ground to reflect and build upon. An example of guidelines from 5.6 is "Textual Minimalism": design for people with Down Syndrome should use as little text as possible, presenting sentences max. 2 words long and using simpler, all uppercase typefaces.

Having User Needs and Design Guidelines (recommendations) clearly outlined was crucial, and allowed decision-making in following steps to be both easier and more streamlined.

4.9 Sketching, Conceptualization and Wireframing

While previous efforts focused on gathering and / or producing insights for the project (problem definement), this step marked the beginning of practical efforts (solution making).

Most of the work for this step consisted in evaluating (previously detected) issues, ideating (interactive) solutions, and laiding down sketches and wireframes – all on paper.

Printed frames, sized as a standard phone window (150mm x 72mm) have been used for all sketches, and results manifested as a set of Low-Quality screen prototypes, featuring a variety of functionalities, mechanics and appearances for the application.

In the end, over 100 alternative screens have been drafted, and for each draft, several looks have been tested.

This step allowed to test ideas in quantity with relatively low time consumption, as well as to detect early in time issues which could become critical at later stages. Ex. As in the case of checking whether a certain number of elements would look "cluttered" on screen (visual density), or too many actions displayed simoultanously would look misleading (visual clarity).

Due to the higly explorative nature of this step, the wide majority of tested (and prototyped) solutions has not been mantained for the Hi-Fi prototypes. Regadless, most interesting concepts have been saved, and might return in future versions of the application.

4.10 Prototyping & User Testing

First attemps of design are rarely successful, or rarely enough. Users might not be able to understand a core functionality, might not be able to find it on screen, or might make unexpected o unrapairable mistakes. In some cases, the whole project will need a realignment. While political changes or shifts in the sensibility of the public are harder to predict, and may still vanify efforts on a project, already present, easy-to-tell weakness should be individuated as soon as it is possible to do.

Iterative Design and Prototyping is the process of developing and testing prototypes over short, fast paced iterations, the intention being to make the most drastic changes as soon as possible in the process, when flexibility is maximum.

For this project, it was crucial to find a concept for an interface that could communicate time to a person with Down Syndrome. Fundamentally, the interface would have to communicate:

i) When is "now" in a day - the placement of living moment in the daily timeline.

ii) What is coming next, and when – awareness of upcoming events and the order in which such events will take place.

iii) How much actual time there is “in between” – awareness of how distant events are from each others, visual understanding of distance in time between two events, of what could be done in such time, allowing for self-management and foreplanning.

It can be observed how there is no mention of describing the speed of time. This is because assuming that time flows at a constant pace[5] , distance will tell us everything that is needed (ex. an hour today will last as an hour tomorrow).

Much expectedly, making an interface that could describe time visually was challenging, and required several iterations before success. A total of 5 iterations have been completed in total, each one consisting of i) designing a prototype (representing a timeline for the day, and the living moment, visually) and ii) testing the prototype (with a pool of users with Down Syndrome who struggle with time perception and the use of digital clocks), iii) structuring knowledge gains from testing, and restarting from i).

Due to COVID-19 restrictions, only 2 users with Down Syndrome have been involved in testing iterations. While more testing will likely be necessary in the future, it can be observed how, according to Nielsen Normann Foundation [], user evaluations in fast-paced prototyping should rely on 3 to 5 testers [], 5 being the limit after which testing results start being affected negatively.

A specific challenge posed by having users to test a prototype of a clock consisted in the prototype (inherently static) having to describe real time as it happened. Such challenge translated in much foreplanning prior to any testing taking place, for example, meaning that days before a certain interview, caretakers would be asked informally what obligations the person would have on a certain day. Such obligations would then be used as reference points to tune the prototype, time in the prototype would also be set to match the time of testing precisely. For example, if Prototype 1 had to be tested on April 12th at 10:00, Prototype 1’s interface would be set (days in advance) to show 10:00 and events of April 12th, according to the moment of testing.

It should be noted that all prototype evaluation (testing) for this project was done exclusively with hi-fi prototypes, and outside of initial sketches, no low-fi prototype (ex. paper prototype) was ever realized for testing in this project. The choice was deliberate, as Lo-Fi prototypes require a tester who is able to make an imaginative effort, and is able to mentally “fill the gaps” of a barely sketched prototype, as well as provide feedback accordingly. According to the clinical picture of the condition (see -), people with Down Syndrome struggle specifically with imaginative efforts, and generally require interfaces to be more clear and polished than usual, which means, that any testing performed by using

[5] 5: And that our users won’t undertake intergalactic travels and challenge Einstein’s Relativity theory.

Low-Fidelity (highly sketched) would have likely led to misleading results. The decision had practical implications: producing only hi-fi prototypes required additional effort, as vectorial assets, icons, fonts and images had to be produced for each tested prototype – resulting in a 3 months long prototyping effort.

Hi-Fi prototypes were produced by using Adobe Illustrator (for vectorial icons and elements), Affinity Photo and Design (for drawings), Adobe XD (for prototyping and animation) and Figma (for prototyping and moving prototypes to mobile for testing).

Testing rounds lasted approx. 15 minutes each (tests had to be short, otherwise the interfaces would not match real time anymore). During each round, testers been asked to speak loud of their impressions (Think Aloud evaluation) while testing the prototypes. No no kind of assistance or explanation was provided at any time during testing, and only notes have been taken throughout the process.

4.11 User Interface Design

User Interaction Design (4.7.8) and User Interface Design (4.7.9) are often treated separately in the making of an application, mostly due to the complexity each of such steps represents.
In-between the finishing of every prototype and testing, all prototypes have undergone a process of fine-tuning of the appearance, the intention being to reduce any unnecessary attrition between testers and tested mechanics.

UI Design is the process of refining the visual language of application - not only to make the final produce more aesthetically pleasing, but also to take advantage of another layer of communication, often underestimated in its impact.
An example is provided by the Aesthetic Usability Effect, introduced by Masaaki Kurosu and Kaori Kashimura (Hitachi Design Center) in 1995 [26] , affirming that users will deem more usable or intuitive designs that are more aesthetically pleasing.

Pleasure itself is described as one of the core values for meaningful user experience in many instances, as the UX Pyramid (Figure 4.1) a framework for categorizing UX efforts and tracking process), based on Maslow's hierarchy of needs [27] .

At the moment of refining the UI of each prototype, and make it ready for a real-world audience, several principles of visual presentation, aesthetics usability, had to be considered. Follows a list of the most relevant ones (and what the implications):

[26]: Tractinsky (), 'Aesthetics and apparent usability'

[27]: Taormina et al. (2013), 'Maslow and the Motivation Hierarchy'

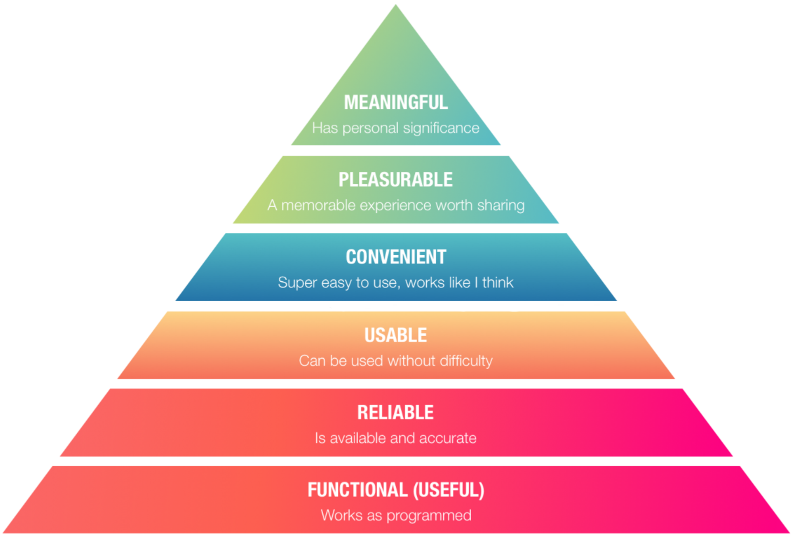


Figure 4.1: Pyramid of User Interface Design priorities. Scale of values based on Maslow's hierarchy of needs. Credits to Marvel blog for the original image.

Color Adjustment for Colorblind People

Modern design inclusivity does regard the use of colors that are easier to be seen by colorblind people. Such adjustments are done by magnifying contrast and tuning saturation of certain tonalities. For this project, all prototype screens have been turned to black and white for fine color tuning, and reverted afterwards - a technique that is often used when arranging visuals for colorblind audiences.

Typography

Use of the most effective and readable fonts. High capped text appears to be first learned by people with Down Syndrome, making it a preferred choice. Simple, roundy fonts typical of early infancy books are also an optimal, familiar choice.

Color psychology

Using warm, reassuring color palettes fosters enagement and makes interfaces more welcoming. For a clock that is expected to be used several times in a day, color psychology plays a significant role.

Branding and Logo Design

Strong branding adds to the possibility that users will be interested in trying the application. Adding relevantly to its real-world contribution.

Visual Hierarchy

The size and position of visual elements should be consistent across screens, and reflect the relevance each element has in regard of the bigger picture. Core elements should be bigger and easier to find. Options should not be intrusive, yet possible to be found if needed.

4.12 Trustworthiness of the study

According to Lincoln & Guba (1990) [28] , a Qualitative Study is considered trustworthy if the following requirements are satisfied:

[28]: Lincoln et al. (1990), 'Judging the quality of case study reports'

(a) credibility (or internal validity)

(b) transferability (or external validity)

(c) dependability (or reliability)

(d) confirmability (or objectivity)

In light of aforementioned details in this chapter, it appears reasonable to think that all of such requirements have been fulfilled to this point. Extensively:

(a) credibility
Can be achieved by performing Data Triangulation (Patton, 2002) [9] , or upholding the interpolation of different sources to produce reliable data.
For this study, different sources have been concerned for Research (as in considering several sources for Existing Solutions or Methodologies) and Interviewing (as when concerning wide sets of experts). As anticipated in (-), Evaluation is much weaker, and included a smaller group (barely 2) people with Down Syndrome. Which doesn't mean that final design efforts are not valid - in fact, all outcomes are solidly grounded in trustable interviews - yet, it is reasonable to say that the project should undergo additional testing prior to the beginning of development. Relevantly, such testing will have to follow on the epidemic situation, which if improved, will make any form of user testing much easier.

[9]: Li et al. (2006), 'Successful experience of people with Down syndrome'

(b) transferability
Maximum transparency has been attempted when describing the research, design and interviewing process, and is reasonable to believe that all efforts from the design process could be replicated with ease. All practical efforts have been clearly described in intention, modalities and content. All interviewed parties have been accurately described, and their rights made clear in text and during interviews.

(c) dependability
While there is no way to guarantee that the exact same opinions will result from a similar investigation under the same parameters, relevant findings appear to been sufficiently redundant both in interviews and evaluation, suggesting such data to be dependable and true to reality.

(d) confirmability
Confirmability for the study is ensured by Audit trial. Details for the processes of data collection, data analysis and interpretation have been communicated throughout the thesis, as well as the reasoning driving the author's decisions and the background of the author himself.

4.13 Ethics

Lastly, ethics. Much expectedly, ethics plays a significant role in a project that focuses on a minority such as Down Syndrome. As members of a minority that struggles with self-representation, people with DS are particularly vulnerable to any kind of abuse, even (if not especially) from those projects that are trying to aid the community itself.

While supporting an humanitarian project, it is quite easy to fall for self-entitlement, and end up overlooking much needed caretaking for the user's data and rights.

Against such pitfalls, this project has handled all users data anonymously. All interviews with users with Down Syndrome have been handled in a playful and relaxed manner, and much attention has gone into making sure that no distress was created, not to social operators - who overlooked every interviewing session - nor to Down Syndrome interviewees.

Once again, all data have been gathered in compliance of the very strict requirements from NSD (Norwegian Centre for Research and Data), and accordingly, caretakers have been asked to agree on a formal statement prior to any interviewing effort taking place. For individuals with Down Syndrome, caretakers agreed in their stead. While not legally significant, approval was asked to individuals with Down Syndrome as well - as a form of respect and as a prerequisite to any interview.

Prior to thesis layout, a study of appropriate language for writing about minorities has been undertaken. While not intentional, misspells may still be present.

Results and Discussion 5

5.1 Problem validation

This first set of interviews aimed at confirming (or disproving) the very basis for the project. Had these claims not been backed by positive results, the project would have not progressed, and this thesis would be discussing a different type of exploration. Specifically, the following claims were put to test:

1. The very existence of a struggle with Time Awareness in people with Down Syndrome (specifically, the awareness of hours, minutes, seconds passing by).
2. (If yes) whether modern digital or analog clocks may be considered origin or integral part of the issue.

Providing respectively a problem and a reason for the project i.e. making of a different, alternative clock for people with DS.

This first set of interviews concerned 15 individuals, including Psychologists, Cooperative Leaders and Caretakers, all of which with years of experience in supporting individuals with Down Syndrome. Insights are organized per question. More on questions is found in 4.7.3. Percentages refer to how many interviewees (out of 15) agreed on a certain statement.

(93%) Yes, people with DS struggle with Time Awareness
All interviewees but one agreed that people with Down Syndrome do visibly struggle with Time Awareness. Most interviewees mentioned that seconds, minutes and hours appear to be particularly difficult, while days are seemingly easier to grasp. Months and years also appear to be harder to understand.

Observation

These insights appear to suggest that people with Down Syndrome do not struggle at perceiving time, but struggle at understanding time as we describe it. It seems to be the most reasonable answer to why a day (delimited by dawn and sunset for everyone) is harder to grasp than, for example, hours (delimited by mathematics, and no other visible hint). The app will try to address this weakness, and make hours, minutes, seconds visible (rather than only described).

(93%) Time unawareness affects lifestyle negatively and severely
Most interviewees agreed that time unawareness brings stress and limitations in the lives of people with Down Syndrome. Mentioned implications included overperforming activities (such as washing hands), being prone to developing addiction to something (TV or Videogames), struggling with sleeping or going to bed at the right time, becoming anxious over an upcoming event, overwaiting an upcoming event and forgetting to take a medicine (or to attend an appointment).

Observation

These claims validate some of the most significant hypotheses for the project, which up to this point, were only based on personal observations.

One interviewee suggested that not being aware of time could be improving the quality of life of people with Down Syndrome, being the source of a more relaxed and happy lifestyle.

(80%) Clocks are difficult tools to use for people with DS
Upon years of training, people with Down Syndrome can learn how to read out time from Digital clocks. Still, reading and understanding are entirely different skills. Most people with DS are not able to tell "when" a certain hour is placed, are not able to compare to different times of the day, or project an expectation based on time as it is numerically represented. Analog clocks considered even more difficult to use, and in most cases, not even time reading is accomplished.

Observation

It can be noted how, the moment a clock begins to require mathematical thinking, it becomes unusable. For Analog clocks is much sooner, are mathematical thinking is implied even in time reading. For Digital clocks, time can be read "as it is", still, it's meaning still requires mathematical thinking.

(100%) An alternative to existing clock based on visuals is needed and absent

All interviewees were positive on the need of an alternative to existing digital clocks. Some mentioned workaround that they are actively using against such issue, as alarms set at specific moment of the day (for people with DS) and flying notes.

(73%) For people with DS, time is mostly defined as a sequence of events
People with Down Syndrome tend to determine time according to commitments in the day (ex. "[activity] will take place before lunch" or "we will [activity] after dinner").

(80%) People with DS appreciate schedules and are generally akin to pre-defined programs
People with Down Syndrome seem to like making and meeting schedules. Calendars are particularly appreaciated. People with DS were described by interviewees as "strongly methodical".

Redundancy of arguments is fundamental for assessing the validity of a Qualitative study. In general, a Qualitative investigation ends when the research is able to detect clear pattens in provided answers, and new (unexpected) insights have become rare. This moment of Qualitative Research is also known as Saturation point (Figure 5.1) which for Problem validation, was reached at around 15 interviews completed.

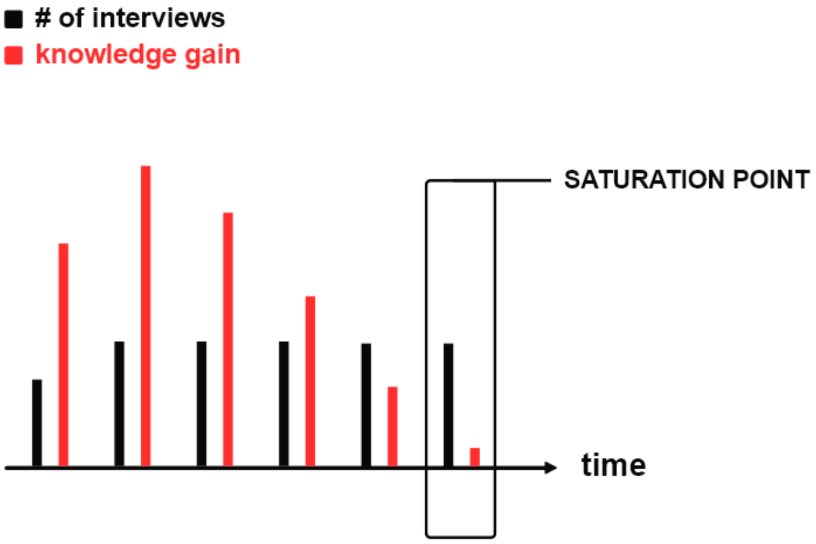


Figure 5.1: Graphical representation of Saturation point. Sketch from the Author.

5.2 User Research - Caretakers

Need Finding consisted of 15 individual interviews, concerning experts caretakers, psychologists, cooperative leaders, clinic therapists and art teachers. Interviews focused on learning habits, needs and values of people with Down Syndrome, insights that would then shape design practices and inspire functionalities at later stages. Follows a list the most valuable insights gained from this investigation. For improved readability, emerging insights are grouped by topic.

Before reading: Validation vs Exploration

It can be observed how data are arranged differently in this case. While Problem validation focused on testing if certain claims were true (ex. 90% agreed on A), User Research's focus is to uncover as many insights as possible. The validity of one specific claim is still assessed, but represented by how many times a certain argument was mentioned. Consistency is assured, as all interviewees have been asked the same questions, under the same modalities.

Legend: (x times mentioned) argument

Practical teaching strategies
(6) Learning is material (not cognitive), and is generally allowed by manipulating and interacting physically with an object.
(5) Repetition is key, and tasks need to be repeated several times to be integrated.
(5) Communication (and learning) must be visual.
(4) Speaking too fast (overloading) is a general reason of communication failure.
(4) Simple, direct language is more effective, both orally and on paper. Long sentences are more difficult to understand and turn into practice.
(2) Relying on familiar concepts or situations when explaining.
(2) Explanations should not be paused or interrupted. Otherwise it is often necessary to start over.
(2) Teaching is more effective if arguments are presented in separate steps, and each step is followed by practical doing.
(1) Show an action being taken, rather than telling how to take it. Rely on the person's ability to mimic an action.

Social-emotional teaching strategies
(6) Keeping a playful, positive attitude.
(5) Rely on humor for the delivery of concepts. Humor is core in communicating with people with DS.
(5) Rely on personal involvement for the delivery of concepts. Make the argument "personal".
(3) Rely on empathy from the other side, explain your needs and

present the interaction as a way to be helped out.
(3) Be encouraging. Address successes rather than mistakes.
(2) Build up interest, fuel curiosity.

Frequent challenges of teaching
(3) Keeping attention high, keeping arguments of a conversation engaging.
(3) Balancing when to have a playful attitude, and when to be firm with requests.
(9) Provoking and understanding feedbacks (most people with DS will just try to accommodate the opponent in a conversation, making it more difficult to tell what is being understood and what not).
(2) Be creative with providing motivation, or explain why something should be done.
(2) Prevent automatisms[1] in answers and / or tasks execution.
(1) Prevent the person from egoistic behaviors or focusing only of oneself's needs.

Common mistakes when teaching
(10) Treating the person as a child. Generally, people with Down Syndrome need to be talked to as adults, only with additional calm and patience.
(6) Asking for straight-up confirmation (yes/no), rather than demanding a more elaborate answer. Straight up answers make of an easy escape from the conversation, and should be avoided when possible.
(4) Being excessively assistive, to a point that the person is prevented from making mistakes and learning form them.
(2) Projecting one's own uncertainties over the person with DS, rather than having a relaxed and calm attitude.
(1) Rewarding a negative behavior, sometimes because of assuming that the person might not be able to do something.
(1) Telling why a certain task is being repeated: in order to be better understood (delayed learning) or because of affection towards repeating the task (comfort of repetition). The latter should be avoided, as (in the long term) becomes detrimental for cognitive development.

Shared behaviors of people with Down Syndrome
(11) Deep enjoyment of music and dancing. For this reason, music therapy is often very successful.
(10) Enjoyment of repetitive tasks, or repetition in general (ex. watching the same movie several times in a day).
(9) Enjoyment of making and meeting plans. Being busy with

[1] Automatisms are responses or actions provided automatically, without much thinking, typically as a result of being used to provide such answer. For people with Down Syndrome, a frequent automatism is to answer "Yes" to any asked question, generally, as a way to avoid the effort of thinking, or to hide not having understood what the other person said. A Caretaker must be completely aware of such characterizing behaviors, and how to counter them.

(self-defined) commitments.
(5) Tendency to focus on human interactions first and foremost.
(2) Tendency to develop exclusive (1vs1) relationships.
(2) Relaxed and efficient use of technology, including smartphones and videogame consoles.
(2) Have overly expansive behavior, and a general difficulty at keeping emotional distance.
(1) Tendency to be competitive, mostly because of emotional investment.
(1) Difficulty at understanding cause-effect relationships.

Frequent stress factors for people Down Syndrome
(2) Being pressured over (ex. Being asked to do something faster or different).
(2) Being interrupted, especially while performing an activity (as painting).

Manifest needs of people Down Syndrome
(10) Feeling listened to, see their contribution in a conversation valued, feel aknowledged, feel included in and part of the community.
(7) Stability. Following a certain routine everyday, and being in control of it.
(5) Being independent, self sufficient.
(3) The feeling of property, control, ownership. Especially for everyday tools or devices.

All interviewees mentioned the central role of family in the lives of all people with Down Syndrome, often crucial for success of failure in teaching (and independence). Lastly, is is relevant to observe how less recurring arguments are not necessarily less valid. While superficial, easier-to-tell traits are certainly easier to detect and present - complex, articulate opinions will be inherently less redundant in interviews.

5.3 User Research - Individuals with Down Syndrome

Need Finding for People with Down Syndrome consisted of 5 interviews with individuals with Down Syndrome, each consisting of 5 questions. Need Finding with experts provided already a solid ground to start from, as such, this effort focused on learning possible conflicts with gathered data up to this moment. Insights come in the form of observed behavioral patterns.

Legend: (x times mentioned) argument

Manifest behavioral patterns
(5) Extreme sensitivity to questions regarding family. In some cases, interviewees lied with the intention to accommodate the opinion of parents (ex. saying that they love something they do not like, something later confirmed being false by the caretaker present during the interview).
(5) Very little patience, need for continuous thrill and engagement.
(5) Need for questions to be repeated in different formulation, since the first time the argument is presented.
(5) Answers were provided bluntly and without much thinking. In any case, it appeared as maintaining focus on a given answer (reflection) was particularly difficult.
(5) Answers were provided with essential formulation, consisting of one (most commonly) to ten words (at most).
(4) Difficulty with grammar formulation, often affecting the complexity of thinking (most interviewees started struggling in the middle of longer sentences, as if the complexity of the argument had become too difficult to keep under control by then).
(3) Need for a strong incentive in order to participate to a task.

Lastly, Time was always described as a list of commitments in the day, and never as something numerical or visual. Upon asking (ex. "When is 13:00?"), numerical time was addressed in function of activites that usually take place at such time (ex. "At 13:00 I have lunch, then, when I finish, I go out for a walk. When I'm back, I watch a movie or do something else. Then there is Dinner,.."). Regardless, it appears that, even in such cases, numerical time was only used as a label (ex. "13:00", but could be "Lunchtime") and never according to its numerical (descriptive) potential.

It can be observed how some behaviors were vastly shared among all participants, suggesting such patterns to be particularly strong. Significantly, most of such traits coincided with the clinical picture of Down Syndrome as it is described in researched publications (2.1), by experts in Problem validation(5.3) and in Interviews with Caretakers (5.4).

In conclusion, there seems to be very little conflict in between findings of this investigation, and findings from Interviews with Caretakers, suggesting an overall solidity of produced knowledge gains.

5.4 Synthesis of User Needs and Design Guidelines

Follows a complete list of design guidelines synthethized from findings up to this points. At anticipated in chapter (4.8), relevant findings are organized between User Needs and Usability Guidelines, serving different purposes.

User Needs (values of people with Down Syndrome)
Is a list of values that are desired and needed by most people with Down Syndrome. The designer should be mindful of these elements, and work on design solutions that prevent conflict with these values, or do so with adequate command.

1. **Social inclusivity and desire of parity**
   Be included, be part of the community. Strive, fail and enjoy things as other people do.

2. **Positive reinforcement**
   Be supported, be rewarded frequently and positively.

3. **Independence and self-management**
   Be able to begin, manage and complete an activity alone.

4. **Respect and self-determination**
   See their choices being respected as the ones of anyone else. See their needs (and requests) not being undermined by their condition.

5. **Ownership**
   Have things that belong directly and exclusively to the person. Be in charge for the maintenance and safety of such things.

It can be observed how all these elements represent something that lacks in the lives of most people with Down Syndrome. Usurprisingly, these same elements have become for many people with DS a testament of their difficulties, and are where most of the work on dignity and emancipation for the community can be done.

Lastly, it can be observed how a clock specifically made for people with Down Syndrome would come to support of many of these values, and make a significant contribution where is most needed. Precisely, being unaware of time can be seen as one the major inhibitions to independence for people with Down Syndrome.

Analysis of existing design guidelines

Making a novel set of design guidelines has required a specific study of existing guidelines, and what they provide. While users and tools may change, the intention of what is a good design will most likely stay the same across devices or uses, as it does the definition of a positive, successful user experience.
Prior to making any design guidelines, the following existing guidelines have been taken as a reference:

1. Nielsen Heuristics (from the Nielsen Normann Foundation)
2. Universal Accessibility Guidelines
3. Thirteen principles of display design by Christopher Wickens
4. Shneiderman's Eight golden rules of interface design
5. Three Limits to Response time by Jakob Nielsen
6. Jakob's Law
7. Fitt's Law
8. Doherty Threshold
9. Occam's Razor

It appears that all of these guidelines try to provide the user with 4 core elements, namely:

1. **Understanding**
   Awareness of what and how something is happening in the system.
2. **Control**
   The degree and amplitude to which the user is able to start, interrupt and pause all content and procedures in the system. Control is enhanced by ease of use, accuracy and responsiveness.

3. **Error Prevention**
   The extent to which the system is able to anticipate, compensate or repair user's mistakes.

4. **Pleasure of Use**
   The emotional state that the system is able to lure the user into. Can be seen both as a parameter for success of UX or a cushion to compensate likely shortcomings from other values.

Understanding such values has been one of the core steps in the making of FRAGILE Design guidelines. Other considered sources have come from Interviews (from previous steps), the medical profile of the Down Syndrome condition and publications on teaching and learning behaviors for people with DS.

Design Guidelines or "FRAGILE" Design Guidelines (what is needed by design for people with DS)
The following design guidelines represent a set of recommendations for the making of digital artifacts that wish to be effective and easy to use for individuals with Down Syndrome.

1. **Minimal, straight communication**
   Use short, simple words and sentences. The delivery must be upfront and direct.
   (ex. Sentences of 1, max 2 words, and straight content, appear to work particularly well).

2. **Delayed response time**
   Expect delayed response time, about 2x of what is traditionally adopted. This principle applies to expiring messages, text-to-speech (calmer), animations (slower).

3. **Provide choices rather than questions**
   Avoid open-ended questions, when possible, provide choices or suggestions. The user should never be expected to perform a creative act when asked for an input. Number of options should also be as limited as possible.

4. **Limit use of UI/UX standards**
   Avoid making exclusive reliance on design convention as a way to communicate meaning. Applies to standards for visual elements (ex. Three dots for options), gestures (ex. Touch to stop a video, swipe left to go back and right to go forward), color coding (ex. Red standing for delete/bad/wrong), and

more. Representations that mimic real-world interactions are much more likely to work, especially if very direct (ex. Rather than a trashbin, show the document itself being destroyed).

5. **Rely heavily on repetition**
   Expect the user to enjoy repeating a task in the same way, several times. Use repetition to teach or reinforce core tasks or concepts in the interface. Expect any repeated textual or vocal message to hardly be irritating for the user, especially is portrayed positively.

6. **Provide positive reinforcement**
   Provide the user with constant emotional reward. Kind and positive words, calm and cheerful music and pleasant color palettes are very likely to be appreciated.

7. **Rely on visual and physical metaphors**
   Cognitive leaning for people with Down Syndrome is mostly related to manipulation and visual memory. Design elements or interactions that mimic familiar objects or contexts from the real world, and allow the user to use them similarly. Avoid abstraction if possible.

8. **Provide feedback for any action**
   There should never be two inputs in a row without any feedback being provided in the middle. The user should be able to tell the consequence of his/her actions by a glance. Any user interaction should be followed by a self-explanatory reaction from the interface.

9. **Avoid or reduce modes[2] to minimum**
   People with Down Syndrome experience specific struggles with memory, as such, the use of modes and modal errors in general should be minimized. If modes have to be introduced, it is important to make them extremely explicit, and hard to be ignored (high in visual hierarchy).

10. **Expect reduced precision in physical interaction**
    Design wider touching areas (less precision required) and expect the user to be more likely to make a mistake when physically interacting with the device. Interfaces should also take into account that people with DS have slightly shorter limbs.

11. **Engage the user on a personal level**
    Everything in the application should be motivated emotionally rather than rationally (ex. instead of having the interface

[2] A mode in design is a distinct enabled setting affecting the outcome of actions performed within the system (ex. changing which brush is under usage in a painting software will enable a mode, and change the result of brush strokes).

to tell the user what to do, display a character who asks the user a favor by calling him/her by name). Avoid abstraction and formality.

12. **Consider humor to create engagement**
    Preferably visual and childish / explicit. Consider humor the strongest engaging element, and rely on it accordingly.

13. **Consider music and dancing to create engagement**
    Both are vastly appreciated by the Down Syndrome community, and are extremely valuable tools to create engagement or motivate the user (people with DS need strong incentives to begin or continue a task).

14. **Design for caretakers**
    Remember to design areas (or elements) specifically targeting caretaking figures, which in most cases will be present throughout the app journey, and will likely try out the interface first hand. These might include functionalities, options or information of variable relevance in the app. In some cases, these areas should be protected from the main user (Ex. The person with DS might accidentally access and change options).

Following the publishing of the thesis, these guidelines will be rearranged and published as a web article on the Medium platform, the intention being to support similar project, and perhaps sparkle a dialogue on the absence of principles addressing design for people with Down Syndrome.

5.5 Sketching, Conceptualization and Wireframing

Early sketching and conceptualization consisted of proof testing ideas and learning about crucial aspects (and limits) for the app early on, mainly by seeing how such mechanics would work visually on paper. In the end, this effort consisted of making over 100 sketches, some rough, some very detailed. Hereby are reported some of the most crucial arguments evaluated, most of which concern the logical structure and representation of time for future prototypes.

Time geometry: showing time as something linear (rather than cyclic)

Finding a visual representation for time means finding a representation for something that grows linearly, flows at a constant pace and operates in cycles (hours, days, years). As a result, a crucial aspect consisted of deciding whether time had to be represented as something linear (similarly to a progress bar), or cyclic (akin to analog clocks). In the end, it was decided to use a linear time representation. This because:

- Circles do not have a clear starting and and ending point, making more difficult to read the linear progress of a day (v/s linear representation, where a day starts, runs to the right and ends very clearly).
- Circles don't allow scrolling, which is very likely to be needed as phone screens offer minimal real estate, people with DS need big images and text, and daily timeline might be filled with multiple events (v/s linear representation, which can be scrolled in 4 cardinal directions).
- Circles don't allow zooming. While technically possible, zooming on a circle would result on losing sight of the overall shape, making visuals and progress in general overly complex (v/s linear representation, where regardless of scale, progress will always be found on the same side.)

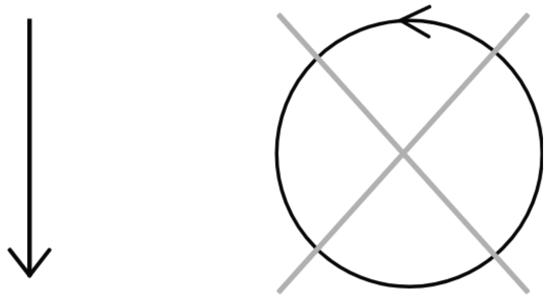


Figure 5.2: Linear progress appears to be more intuitive than cyclic time. Image from the author.

Layout orientation and direction: time goes top-bottom on a vertical axis

A different kind of challenge was posed by the device chosen for the application: smartphones are compatible with vertical and horizontal orientations. In this merit, it was decided that:

- The app would be visualized only in portrait mode (vertical), This is because a clock is something that is meant to be used on-the-go, and vertical is the standard mode for phones.

- Scrolling in the app (in order to see more of the timeline) would go top-bottom, with present time being at the top and immediately visible on app bootup, and future time (and events) found lower in the UI, eventually accessible only by scrolling.

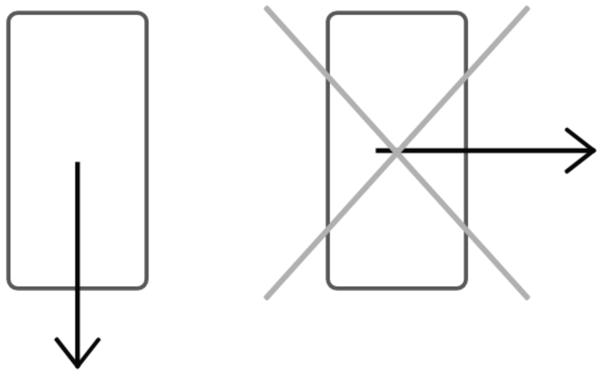


Figure 5.3: Vertical scrolling appears to be a better choice than horizontal orientation. Image from the author.

Referencing time: daily events as contextual milestones

When asked to describe the living moment "Q: what time is it now? What do you mean?" , most interviewees with DS referenced to themselves as approaching a familiar event (“it’s almost lunchtime”), rather than using any numerical annotation (“we’re due to 13:00”). When asked to describe time, proceeded to list all relevant events that they would commit to on that same day. This representation of time is a comfort language for the user, and is resembling of how time is likely to look and feel in their minds, The app’s UI would mirror this understanding of time, presenting a (linear) timeline featuring daily events as reference points. The idea being of creating a visual representation for time that is closer to how people with Down Syndrome already see it in their minds. This representation would then be used as a starting ground to provide users with those elements that are less clear, such as distance in time (ex. The proximity of an upcoming event).

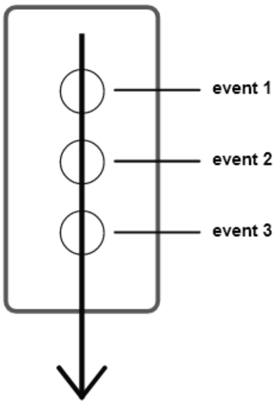


Figure 5.4: Segmenting time in milestones makes progress engaging and easier to understand. Image from the author.

Visualizing distance and progress in-between events

Once milestones are set over the course of a day, users need to be provided with a feeling of how far away in time these events are from one another. In other words, distance in time has to be portrayed visually.

This phase concerned itself with finding the most efficient way to represent the distance (and later progress) that will intercour between an hypothetical event A (ex. Breakfast) and an hypothetical event B (ex. Lunch). There are several ways to represent this distance, such as lines, dots, numbers, dashed lines and symbols. Generally, design addressed elements that describe progress in time as Determinate Progress Bar Indicators. Examples of DPBS are progress or loading bars, such as the ones prompted to the user during installations or downloads. For this project, the intention was to find a progress bar that would be clear by a glance (maximum accessibility), but still include a reference to the number of hours left to an activity (letting users develop a feeling of what hours are, over time. Mostly for social inclusivity reasons (see value of "Social inclusivity and desire of parity" introduced in 5.4).

In the end, variants of the following concept have been used in most prototypes:

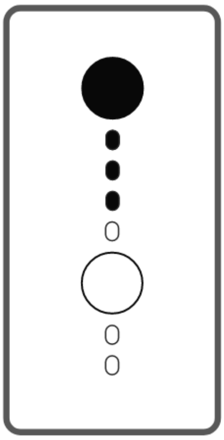
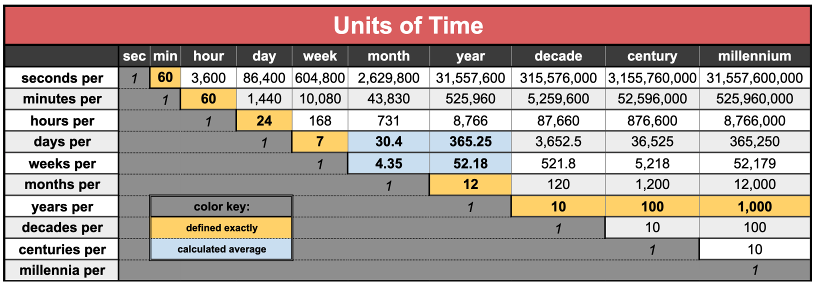


Figure 5.5: Progressing time is displayed as a progress bar broken in segments. Image from the author.

Which is assimilable to a dashed progress bar, or a bar broken in multiple pieces, each one representing a the same time unit (later on decided to be 1 hour).

Finding the smallest time unit to represent



Units of Time

	sec	min	hour	day	week	month	year	decade	century	millennium
seconds per	1	60	3,600	86,400	604,800	2,629,800	31,557,600	315,576,000	3,155,760,000	31,557,600,000
minutes per		1	60	1,440	10,080	43,830	525,960	5,259,600	52,596,000	525,960,000
hours per			1	24	168	731	8,766	87,660	876,600	8,766,000
days per				1	7	30.4	365.25	3,652.5	36,525	365,250
weeks per					1	4.35	52.18	521.8	5,218	52,179
months per						1	12	120	1,200	12,000
years per							1	10	100	1,000
decades per								1	10	100
centuries per									1	10
millennia per										1

color key:
defined exactly
calculated average

Figure 5.6: Units of time in tabular form. Credits `https://upload.wikimedia.org/wikipedia/commons/5/50/Units_of_Time_in_tabular_form.png`

Deciding which would be the smallest time unit to represent in between events was also a significative challenge. The ideal STU for the application responded to the following requirements:

1. **One digit Integer**
   Not the half, nor the double of anything (ex. not half an hour or 40 seconds, but rather one hour, one minute, one second). Behind such choice, a simple reason: this unit would be represented as one single element, and referencing it as any quantity other than “1” would have resulted in contradictory information.

2. **Frequently referred to in conversations**
   Being the base unit of time in the app, it needed to be frequently used to refer time in between activities by individuals with Down Syndrome and people in general.

3. **Reasonably big**
   Smaller time units translate into more single unit elements

on screen, a choice that goes the expense of either readability or a loss of screen estate. Using a bigger, easier to represent unit was preferable.

In the end, 1 hour has been taken as the standard unit in the majority of prototypes.

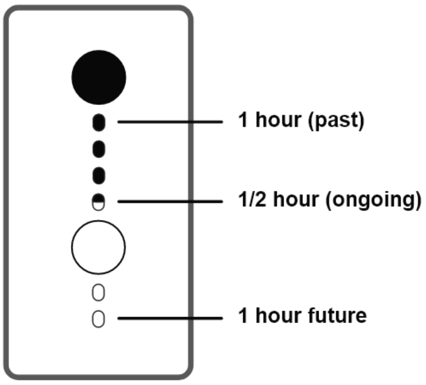


Figure 5.7: Progressing time is displayed as a progress bar broken in segments of one hour. Image from the author.

Design of the app for two userbases

Lastly, it was decided that the application would operate in two distinct modalities, one addressing Caretakers (or "planning mode") and another one addressing users with Down Syndrome (or "presentation mode").

In "planning mode", caretakers would be allowed to program events and reference points to be shown by the clock to users with Down Syndrome.

For example, a caretakers would be allowed to use the "planning mode" to set that "breakfast" and "lunch" will typically take place at a certain time on Fridays, then, the user with down syndrome will see such events automatically pop in when the day is due, and build an understanding of time as it flows. Events could be "basketball lesson" or "watching Firefly on tv" or again "taking a medicine". It should only be remembered that focus is not primarly on taking note of these events, but rather on finding trustable references to support the cognition of time.

In "presentation mode", time is presented to users with Down Syndrome according to the programming from caretakers, parents or for advanced users, even themselves.

This separation could be seen as a distant relative of Powerpoint presentations, where crafting and visualizing concepts takes place in separate instances, and with different tools.

Having this kind of separation was also inevitable. While existing digital clocks are impersonal, minimal and not bound to any context (which makes them difficult to understand), these characteristics also make of them highly efficient tools, compatible with any environment and needing of very little maintenance. Describing time as something personal, contextual and explicit means that someone needs to take care of these elements – a work which will be compensated by advanced users who will be in charge to "tune" the clock.

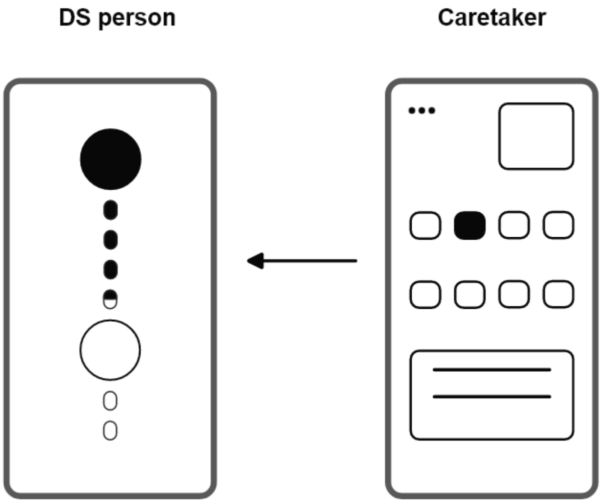


Figure 5.8: Modes expected for the app and relative users. Image from the author.

5.6 Prototyping & User Testing

First prototype

Premise on the first prototype

It can be observed how many of the struggles caused by time unawareness (ex. anxiety or overwaiting) are first and foremost caused by the user's inability to tell (when in time) the next obligation will take place. In other words, it is not as important for the user to be aware of the complete timeline, as it is to be informed of when the next event in line will happen i.e. if there is concretely time to do something else – this is because, not being aware if there is time do something else, the user is prevented from starting new activities, and remains trapped in a state of waiting until the planned commitment takes place.

Description

The first prototype focuses on conveying the feeling of urgency of an upcoming task. Elements are presented with a clean and

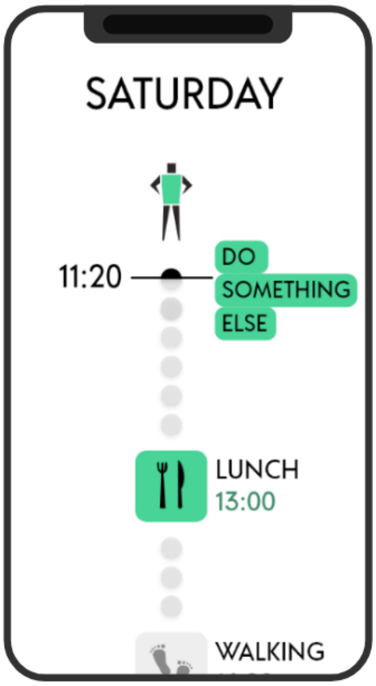


Figure 5.9

minimal look. Only elements contributing to the concept are presented on screen (there are no instances of images, icons or visual elements which are only decorative). Also, it can be observed how only elements bound to present time are colored (everything else is presented in black and white), this is done to reclaim the user's attention on those elements that bring the most relevant information (Visual Hierarchy). The interface features the following elements in reading order:

Week day: is the first element seen by the user. The text not only informs the user of what day it is, but also that the timeline will represent only that one day i.e. the timeline does won't go any further.

Character: similarly to what happens for physical maps in facilities ("You are here"). Tells the user in the most straightforward way that she / he is part of what the app is representing*, as well as that she / he is a specific place at that moment – where the character is. This application tries to create a visuo-spatial representation of time, as such, placement in space will always anticipate placement in time. Using a character also fuels engagement, and opens to options such as customization for future iterations of the app.

Time: represented in three different forms - numerical, visual and verbal – for maximum throughput*. Presenting time three time is also repetitive (guideline 5: "Rely heavily on repetition", 5.4), and goes to the benefit of those users who understand partially or completely more than one representation.

Color coding: colors represent connection, priority and urgency of the message. In reading order, green tells that "you (character) should do something else (message) before lunch (icon)". This is never said bluntly by the interface – it's the composition of elements gathered by color that conveys the meaning. Similarly, yellow will communicate a commitment that is fastly approaching (but not imminent), and red will say that the commitment is happening anytime now. The hue** of colors is not casual either: green is the psychological color of foliage, safety and recovery, yellow is a warning, red is danger and immediate awareness (fire) – taking decision in respect of such principles is also called Color Psychology.

Icons: icons convey the visual identity of upcoming events in the day. Earlier versions of this design could see emojiis being used in place of icons – a choice both convenient (there are plenty of, the

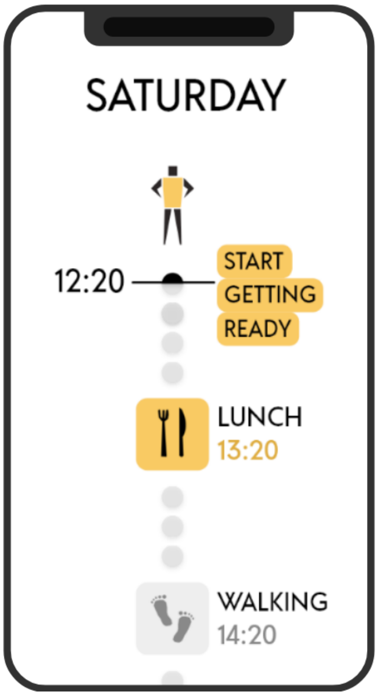


Figure 5.10

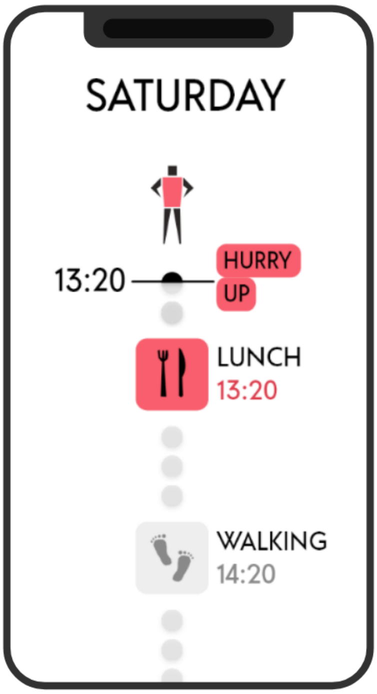


Figure 5.11

majority of which is free to use) and easy to implement.
Unfortunately, emojiis create visual clutter when placed next to each other, which led to making a specific set of icons purposefully for this prototype. Icons have been created as vectorial elements. Each shape was composed of max. 2 interpolated sub-shapes (toning down visual clutter), and designed to work efficiently in black and white (not relying on color communication).
Compared with all-purpose emojiis, it is possible to see how much visual clarity has benefitted from the effort.

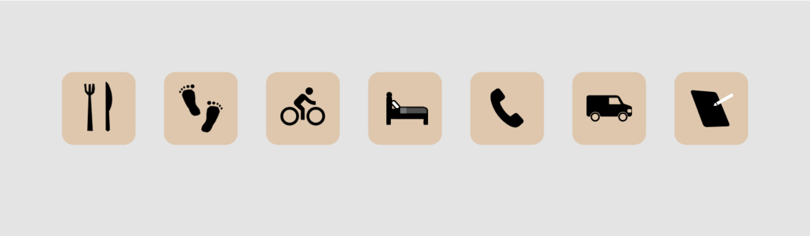


Figure 5.12

Results - what worked
Users did read the day title first (as expected), and understood that the application was displaying that specific day. Users did identify themselves as the character ("this is me!"), and realized almost immediately that numbers surrounding it represented the living moment. Icons were understood easily as well. Color coding seemingly succeeded at highlighting content.

Results - what didn't work
In general, users were not able to timetell using the prototype. More precisely, timetelling only came in the form of reading time in its digital representation (failure). Users seemed to focus on familiar elements above all, and escape the effort of understanding new concepts if possible. From the moment users did find time in its classical notation (ex. "13:20"), they stopped trying to understand how it worked or what it represented, only addressing the design as a clock, and considering the interaction over by reading out loud time in that notation (ex. "it's 13:22, this is it"). Icons offer another significant example: users did understand icons almost immediately (ex. Eating icon), but refused to read what those same icons represented (ex. Lunch) once provided with an overall understanding of the meaning.

Conclusions
Familiar concepts are a two edged sword: on one side provide individuals with an easy route to understand mechanics, on the other, may hide originality or even be misleading of a concept's true identity. In this case, the abuse of familiar concepts, and the decision to provide the same information over different layers,

encouraged users to only look at easiest, most accessible objects, resulting in abare-bore and superficial use of the prototype.

Second prototype

Description
The second prototype sacrifies part of the minimal aestetics to provide a more engaging look, wanting users to focus on activities (brown panels) above all. Visuals feature a warm and welcoming look, inspired by the colors of Japanese ryokan (traditional housing of the Edo period*).
Compared to the previous prototype, users are now allowed to navigate and see timetables from future days, a feature that was envisioned early on, but yet to be introduced.
A button leading to planning mode (the "programming" modality for displayed events) has been introduced in the top right of every screen. Regardless, the design of such modality would have to wait for the presentation mode (and its elements) to be already definitive.
It can also be observed how, compared to the previous prototype, past events do remain visible after their completion (until the day ends) – this is done to compensate the absence of a character (that used to provide context), which was removed temporarily from this design.
In general, this prototype worked as an experiment to see how effective would be a design were all distracting or familiar elements are absent, from which the absence of a character (distraction), icons (distraction), sentences informing the user of time left (ignored or time consuming) and time in its iconic, digital representation (misleading). The result is a design where the user is forced to understand what the application is, and is not offered any shortcut. In logical order, the design wants users to focus primarily on how many hours are left (yellow blocks), reasoning out that the blocks refer to the upcoming event (lunch) by proximity.
Looking at previous events, the user will also find that those events – the same that have just passed in time – display a green check (missing in upcoming events) suggesting by visual comparation that those unchecked events still have to take place.
It should be noticed how "1 hour" works as the clear standard unit in this prototype (motivated in -) and how smaller unit of time, conceptually "half an hour" or "a quarted of hour" are visually represented as a split section of the hour segment, requiring users to only make sense the basic hour concept.

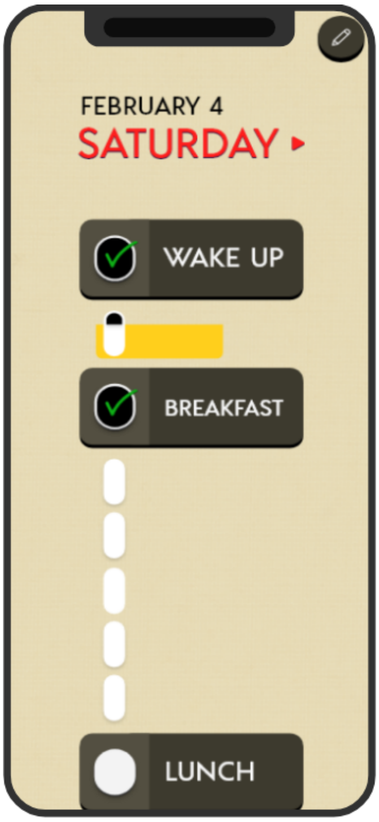


Figure 5.13

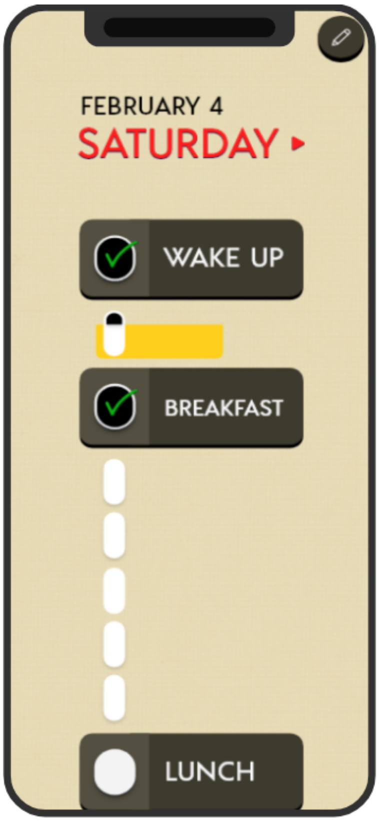


Figure 5.14

Results - what worked
Results were encouraging at first, with users immediately calling

out yellow marks, and identifying both left hours in the prototype as a single quantity: two hours (grouped by color). Users also understood that the same two hours represented time left prior to the event ("lunch"). Lastly, users identified past events in the day as previous panels (checked in green).

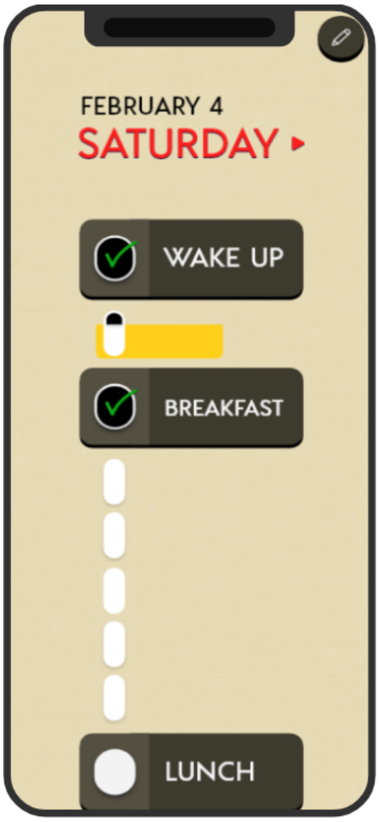


Figure 5.15

Results - what didn't work
Users seemed to understand that a certain quantity of time (two hours, highlighted in yellow) was positioned before the following activity (lunch), but never addressed the quantity of time (two hours) according to themselves, or according to any positioning in time. When asked "where are we now?" or "were are you here?" or again "what time is it now?", users were not able to see themselves on screen, and instead kept looking for any numerical annotation of time (ex. "12:00"). In other words, users never seemed to find themselves in the timeline, and only "read" the interface as a list of elements detached from context.
Lastly, all users needed the interviewer to scroll the interface in their stead, and center it on present time (yellow blocks) before the beginning of testing - suggesting that either automatic scrolling should be introduced, or the app should go back to representing only present and future events – as a reinforcing factor, past events were noticed at last, and didn't seem to contribute to the overall understanding of the app.

Conclusions
Users kept looking for numerical annotation in the design, but most importantly, didn't seem to be able to address time verbally without the use of such notation – this last point is particularly relevant, as in fact, up to this point, the design had not provided users with a way to speak out time, and only cared to find a way that could represent it visually in a meaningful manner. This test brought clearance on the fact that time is not only a contextual concept (premise of the study), but it is also a social concept. And especially for people with Down Syndrome (Values: Social []) there is no actual use in providing a time representation that is clear (against digital clocks, which are not), if the same representation doesn't also allow users to describe time verbally or communicate time to others (as in cooperation and participation).

Third prototype

Description
The third prototype adopts a neutral color palette, using accent colors (such as green) and darker tints to highlight meaningful

content. Compared to previous prototypes, this design has benefited from additional care in the making of visuals, which are not only amenities, but provide actual ease of use according to the expected fruition of the prototype. For example, it is possible to tell by a glance whether there is free time in-between two activities, mostly thanks to the color coding of activities (black stands for "busy" and white stands for "free").

After the first two prototypes, it seemed as, regardless of the initial intentions of the project, most of the designs kept presenting conceptual elements (time) as merely something visual, rather than trying an actual physical metaphor for the concept. In other words, the difference being between trying to paint something abstract resembling the abstract concept (ex. "gym" as a checkbox that fills at a certain time) and trying to come out with a physical element that embodies the properties of that concept, and then use such element as a visual representation (ex. "gym" is an island that is a approached by the character at a certain time).

This design tries to break free from such cycle, bringing a representation of time that tries to be more physical. While still minimal in its appearance (also because of practical constraints in the creation of more personalized "activity islands"), this prototype appears significantly less abstract than the ones that came before. /For this project, a significative challenge is clearly to design a time representation that is enough abstract to be compatible with different scenarios, and enough personal to be empathized with from users with Down Syndrome./

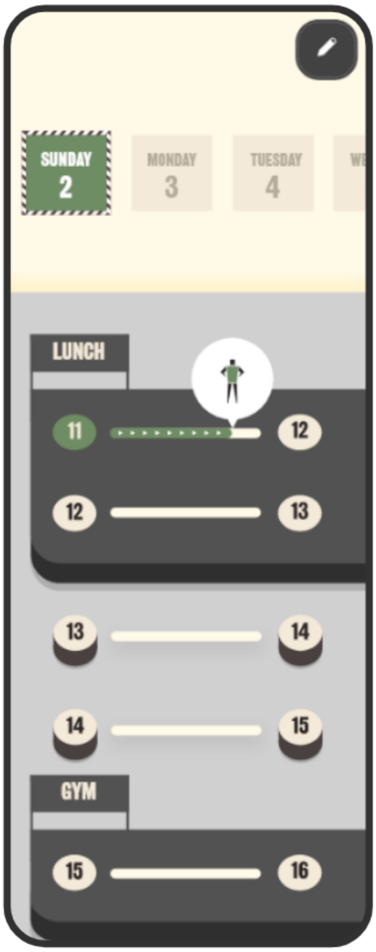


Figure 5.16

It can be observed how the design still uses single hours as base time units. In the end, the choice appears to be a winning one, as progress by the minute is visible by eye with bars of such size and progressing at such speed. Regardless, it can be observed how the green progress bar for time features a set of little, white arrows. These arrows are supposed to be animated further on (not in the tested prototype), and provide a reinforced visual feedback of progressing time.

Once again, the interface features a character that is supposed to impersonate the actual user (character customization may be added in future iterations, but earliest design are planned to be anonymous and gender neutral). In the final version (not in the tested prototype), the character is supposed to replicate the action taking place at that moment (ex. Brushing teeth for the right amount of time, or training at the gym).

Users are allowed to navigate in-between days by touching on the respective postcards on the upper side of the interface (green cards, ex. "MONDAY"). Looking at the daily timeline of a specific day, users are also allowed to create memos on the timeline by touching any point of the timeline. After touching on a certain point, users will be shown by the window at Figure 5.17, from which details regarding the memo can be adjusted at will.

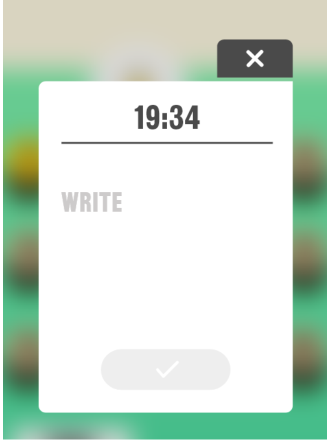


Figure 5.17: Prompt window for creating an alert on the timeline.

By default, the application will set the memo to run at the time responding to the area on the timeline intially touched by the user (ex. User touches in the middle of the platform 19 and 20, resulting in “19:34”).
In practice, the user is only required to write (at least) a word in the textbox ("WRITE"), and then will be allowed to conclude the interaction already.
A memo will be created which will play at that specific time, displaying the text previously inputed by the user.
This process has been conceived to allow those users who do not understand the numerical notation of time to still be able to create and set a memo. For those users who do understand time in its numerical notation, or that are asked by a third party to set a memo that rings at a specific time, it will only be required to change time on the memo before confirming, overwriting the intial suggestion based on where the user touched on the timeline (change “19:34” → “19:40, Figure 5.18).

Once created, a memo is represented on the timeline as a small speech balloon uttering three dots. This design was preferred at the end of a long process of design and selection.

If activites that take place during a certain interval are represented in the application as islands (black-tinted blocks), memos are meant to represent actions that take place at once. For example, taking a medicine, making a call, dressing up are all considered actions.

Lastly, there are some additional observations to be made in relation to the look an communication of the design. For what concerns

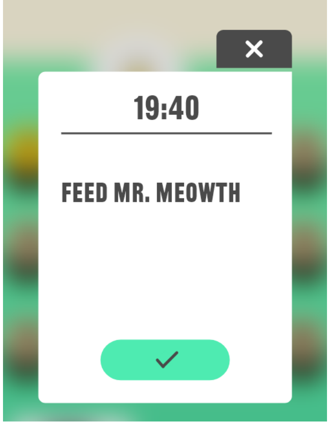


Figure 5.18: He loves it.

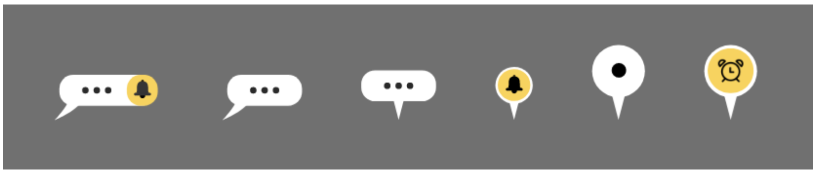


Figure 5.19: Modes expected for the app and relative users. Image from the author.

color coding, it was explained previously how white stands for free time, and black signifies being busy. Another color that is prominent in the interface is green, which stands univocally for present time. It can be observed how current day is highlighted with a green, as is the progress bar (of the living hour), and the character impersonating the user in real time.

Looking at the exterior of the interface (Figure 5.16 and Figure 5.20), it is clear that the design makes wide use of numbers, and it would be reasonable to wonder if that goes against the intial premise of the project: making a clock that doesn't use mathematics or abstraction. By looking at Figure 5.21, it is possible to see how even if deprived of any number, all time-related information portrayed by the application remains intact. Without numbers, a user with Down Syndrome is still allowed to see how much time there is left before the next activity, the overall timeline of the day, where he/she is in time, what weekday it is and how fast and at which point the current hour is expiring. Numbers are employed by the design, but only as labels that allow users to refer (and discuss) time verbally. Icons or colors could be used in place of numbers, and the overall mechanics described by the application would (supposedly) not vary.

Prior to moving forward, it can also be noted how numbers are displayed only according to the first two digits "11", rather than in complete digital form "11:20", this is done to reduce the overall quantity of numbers on screen (preventing clutter), and also because users with Down Syndrome (and users having math difficulties in general) are much more familiar with basic counting (one, max two digits). Lastly, information from the other two digits (ex.":20") would be redundant, as the information is already

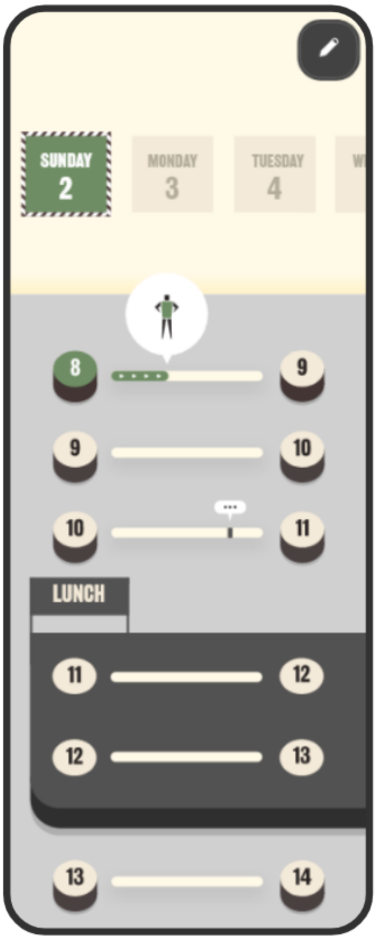


Figure 5.20

addressed visually by the progress bar.

The design presents time flowing in reading order, moving left to right (as the living hour passes, and the bar fills in green) and left again (as a new one starts), as if evolving time had to draw a "Z", or an "F" on screen. The structuring is not casual.
According to the Nielsen Normann Group (2006 []), users have a predisposition to read (or "scan") pages according to a specific order, which the study addresses as "F-pattern".
In this prototype, the placement of bars (the overall "direction" towards which time develops) has been designed to reflect the "F-patten", in a way that even in absence of numerical notations, of color highlights (ex. green for progressing time) or suggestive animations - all of which will be part of the final application - users would still be brought to read the app in the "right order".

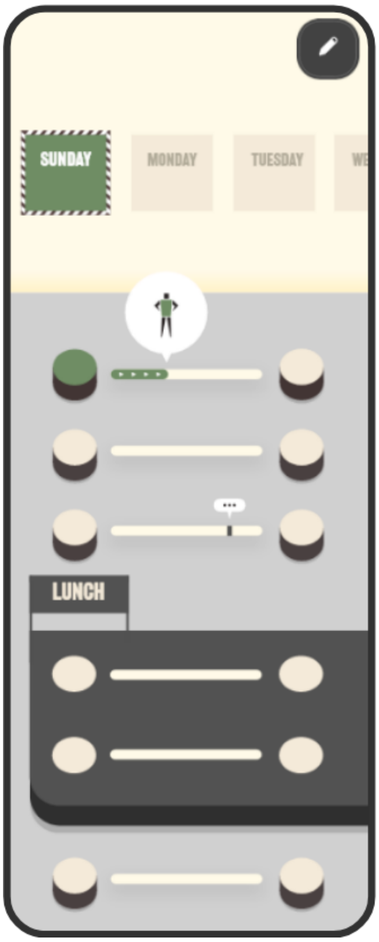


Figure 5.21

Results - what worked
This is the first prototype that succeeded at its scope. By a glance, users managed to find themselves on screen ("this is me"), pointed out where they were in time ("we just came past 11"), and looked spontaneously at moments coming after in the day ("this is when lunch happens!"). In a way, the prototype went far beyond expectation, as at the end of the testing phase, both users asked to have the application of their phones as well (it was never declared for it to be a prototype). This is significative, as it means that users have found themselves in command of the tool to the point of feeling ready to use it without assistance.

Results - what didn't work
Users did appear to struggle a little when reading content on the interface, and in all cases, had to look closely at the screen to read text. In this regard, it appears that future iterations of the design should increase the size of elements and texts on screen.
Other limits did not emerge from testing, yet are inherently part of the specific design of this version of the application.
For instance, the design has been conceived to work with 1 hour long commitments, yet, visual clarity may suffer if users set up appointments half an hour or a quarter of hour long.

Final prototype

Description

The fourth prototype refined and improved over the aesthetics and mechanics of the third prototype, and complied to the intention of translating a solution which worked (third prototype) into a solid ground for expanding and developing. Purposefully, the overall look and feel of this design is much closer to an actual real world product.

Compared to the third iteration, visuals have been zoomed in (to increase readability), contrast of colors has been magnified, minor visual elements have been redesigned in respect of a more minimal aesthetic. It can be observed how where there used to be "islands" inglobating numbers, there are now only tinted platforms. Whether the change will affect the usability of the interface is something that will need to be tested. Regardless, this design allows a much better representation of fractions of an hour – which used to be harder to represent in the previous prototype.

Another change that is possible to notice is how actions (message icon) and events (black tinted portions of the timeline) do now leave similar (black) marks on the timeline, creating a much consistent visual language. It can be observed how in general, this design relies significantly more on colors, rather than shapes. Behind this choice, is also the will to make the design easier to develop at later stages. While programming and development in general should not impose upon design reasoning, it is also true that at some point in time, the prototype will translate into an actual, usable product, and that designs that are easier, more practical to work on tend to be completed, and refined much more frequently.

Interactive prototype (AdobeXD)

Link

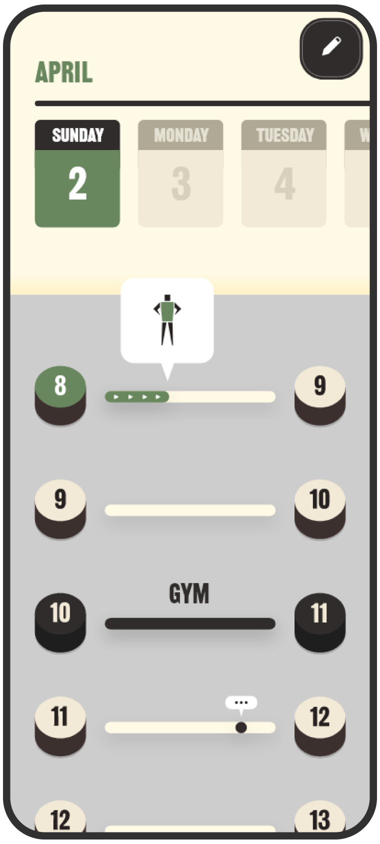


Figure 5.22

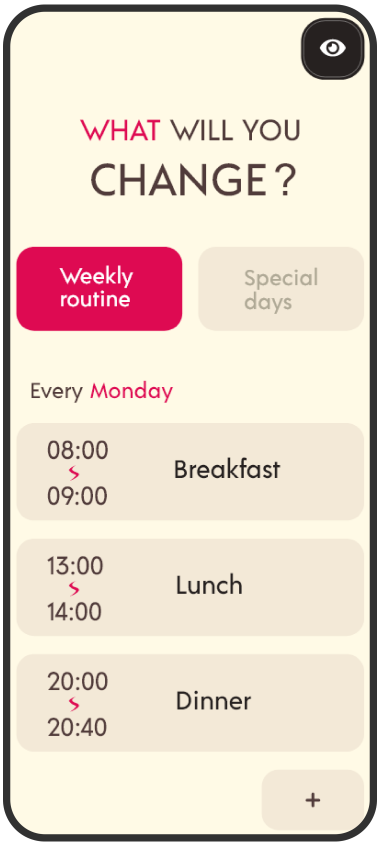


Figure 5.23

Conclusions 6

6.1 Overview

Validating Time unawareness in individuals with Down Syndrome

The project started from the hypothesis (based on observations) that people with Down Syndrome may struggle with time perception, and that such struggle could be attributed to inefficient, unsuitable design of modern analog and digital clocks.

By interviewing 15 experts from separate fields (each with years of experience in working with Down Syndrome), it was strongly confirmed (93% * consensus form Interviewees) that individuals with Down Syndrome do indeed struggle with Time perception - struggle so far undocumented - and that such struggle has a negative impact on the quality of life of individuals with Down Syndrome (93%).
The same investigation also confirmed that time representation offered by existing analog and digital clocks (time is represented as a number) is difficult to use for most individuals with Down Syndrome (80%), and might even be the primary cause of detected time-related struggles across the minority (80%)(Full data at 5.1).

It is also relevant to observe that, according to the clinical profile associated with the Down Syndrome condition (introduced in chapter -), individuals with Down Syndrome struggle specifically with mathematics and abstraction (for example, at holding imaginative constructs in memory[1]), both of which are pre-emptive skills for the understanding of time as it is represented by existing analog and digital clocks.

According to performed research, which spanned over historical artifacts (3.2) , modern devices (3.3) as well as any published research prototype (3.4), outside of early candles in [AD 520] or the observation of shadows moving around objects, no explicit attempt has ever gone in the direction of developing a time-telling device that relied on other than mathematical reasoning.

[1] Also addressed as Short-Term Verbal Memory.

Making a clock that does not rely on mathematical thinking

The aim of the thesis consisted of conceiving, designing and evaluating an novel representation for time that would not require users to perform mathematical or abstract reasoning. Time would be displayed before users as a visual, metaphorical structure, allowing readers to pinpoint (rather than imaginate) places and distances in time.

Conceptually, the interface would rely on perceptual communication (rather than cognition) to translate the complexity of time - exploiting sensorial inputs, such as sounds, colors, spatial separation, body language and aptics - to generate the feeling of time as an instinctual, immediate realization elicited by external stimuli.

Findings from User Research

User-Research is the process of collecting valuable insights - habits, traits, needs or values that belong to people who will use a design.

5 individuals with Down Syndrome (5.2) and 20 experienced caretakers (of individuals with DS)(5.3) have been interviewed as part of the study, being asked skill-related questions in separate settings and sessions.

Knowledge gains took shape as an organized set of qualified opinions, including teaching strategies (from caretakers), social-emotional teaching strategies (from caretakers), challenges to be expected, typical mistakes (observed by caretakers), shared behaviors (in individuals with DS), manifest stress factors (in individuals with DS) and observed behavioral patterns displayed by individuals with Down Syndrome during interviews.

Design guidelines for Down Syndrome

According to preliminary research, design for Down Syndrome is unconventional, and there are no existing design guidelines to guide the making of digital artifacts for people with the condition.

In light of such knowledge gap, research findings have been reorganized the first set of heuristics for Down Syndrome usability, addressing intuitive, practicable interface design for individuals with the condition.

FRAGILE Design Guidelines, found integrally at (4.8), are conceptually separated in two sets.

User Needs - is a set of 5 arguments, addressing the societal and human needs displayed by individuals with Down Syndrome during the project.

Guidelines - is a set of 14 design recommendations, to be used for heuristic evaluation, and to guide the making of novel Down Syndrome-inclusive interfaces.

Upon closure of the project, the same guidelines will also be shared as an online resource, hopefully fueling the dialogue on the need of creating condition-specific design practices (other than universal accessibility) and providing exposition to the special needs that associate with Down Syndrome.

Creating a math-less clock

Prior to proceeding on the making of prototypes, over 100 sketches, representing actions, functionalities and bone-structure of interfaces have been realized by the author (5.5).

While only a minimal part of produced material has been used later in the thesis, sketching proved to be extremely valuable (and time-effective) to decide how the application would work in prototypes.

Decisions taken at this stage included representing time as a linear (rather than cyclic concept), orienting the app in portrait mode (rather than horizontal), using standing-out events in a day (ex. lunch, dinner, gym,..) as milestones to segment the daily timeline, making the app work in two separate modes - one specific for individuals with Down Syndrome (or "presentation mode") and one to be used by caretakers ("programming mode").

Prototyping for the interface took place over a timespan of 4 months, consisting of 4 iterations, each lasting approximately three weeks (4.10).

Over the course of each Iteration, a distinct prototype was produced by the author (first), and then tested by users on a smartphone.

For three iteration, users failed at understanding time as it was represented by the interface. Still, the fourth and last prototype was understood almost immediately form all testers, suggesting a success (5.6).

While interacting with the last prototype users - who were not able to discuss and understand time as it is represented by conventional clocks - displayed an understanding of what the prototype represented (time), and were clearly able to understand distances in time or foretell the cardinality (sequence) of events.

One user, in particular, asked to be allowed to keep the interface for personal use, a feedback which is not only extremely positive, but also shows that the person has understood the value of the tool (after only minutes of use) and feels confident enough to use it without further aid.

6.2 Value

According to testing, the prototype produced at the end of the fourth Iteration appears to be a working alternative representation for time that is understood by an audience with Down Syndrome.

While further testing is certainly necessary, and will take place in anticipation of development, the following experiment is certainly to be considered a success, and may represent the first step to change many assumptions concerning the limits of time awareness.

For once, Dyschronometria has so far simply been addressed as the inability to conceive time - yet, as time is possible to be conceived outside of mathematics - the definition might need to be updated.

But the implications are also practical.

From being able to know when to take a medicine, to being independent in starting and finishing work, as well as training, self-managing diet, or knowing when it is time to go to sleep, the design will bring to people with Down Syndrome the same value that having a clock to read brings in the lives of many.

By the time a practical, final design will be realized and published on the market, some individuals with Down Syndrome [2] might be allowed to live and plan their lives alone, raising their dignity, their self-awareness as well as their chances for an independent living.

[2]: as well as any other individual who experiences similar struggles, finding traditional time unintuitive or difficult to use.

6.3 Partnerships

Tempo has been conceived with the support of TekLab at Media City Bergen, UiB.
Collaborations are also being established with Helse Vest IKT (Bergen, Norway), META cooperative (Rome, Italy) as well as the Italian and Norwegian Down Syndrome Associations.

6.4 Awards

The concept for Tempo (working name of the last prototype) has been awarded a 100’000 NOK grant from University of Bergen, winning the UiB Idè competition for innovative and impactful student concepts. Such funds will be destined for further developing and enhancing the project in the months following the publication of the thesis.

6.5 Responsible Research and Innovation (RRI)

Tempo has been conceived as an ethical, gender-neutral, universal access and open access innovation project.
The application has been designed according to the principles of "participatory design" or "user-centric design" which stand at the core of RRI.

6.6 UN Sustainable Development Goals

The idea behind the project embraces the aims of UN Sustainable Development Goals, promoting good health and well-being (Goal 3) as well as Social Inclusion (Goal 10.2).

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