Design for (every)^{one}

Co-creation as a bridge between universal design and rehabilitation engineering.

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Abstract: In this paper the authors describe a general framework for co-designing assistive devices in a horizontal user innovation network [1] by and for disabled users. This framework attempts to identify, share and use "hidden solutions" in rehabilitation contexts and translate them into disruptive assistive devices build with local resources. Within healthcare contexts local solutions are frequently more effective, as they reflect the physical, emotional and cognitive needs of specific patients and engage all the stakeholders in a specific local context. By using an open horizontal innovation network, where assistive devices can be easily shared and physically hacked by other paramedics, general patterns can be detected and translated into standard universal design objects. This generative design thinking approach [2] is more than feasible with digital trends like crowd sourcing, user-generated content and peer production [3]. Cheap and powerful prototyping tools have become easier to use by non-engineers; it turns them into users as well as self manufactures [4]. We discuss the different aspects of this open innovation process within a 'design for disability' context and suggest the first steps of an iterative co-design methodology bringing together professional designers, occupational therapists and patients. In this paper the authors sketch the holistic framework which starts with the innovation development and the co-creation process between these disciplines.

Key words: co-creation, assistive technology, universal design, open design, personal manufacturing.

1. Introduction

1.1. The history

Within the field of 'design for disability' two main approaches have been emerged in the 20th century. In the late 1960s universal design was inextricably bound up with architectural accessibility due to the rise of some significant federal legislations. As from that moment all buildings that were designed, constructed, or leased with federal funds had to be made accessible. It became clear that many of the environmental adaptations needed to accommodate people with disabilities actually benefited everyone. Slowly it evolved from removing physical barriers to people with disabilities towards integration of all people within all environments. Universal design became a general design approach in which designers ensure that their products and services meet the needs of the widest possible audience, irrespective of age or ability (Ronald Mace,1985). Universal design as a design method resulted in a set of general guidelines and accessibility standards on different scopes which can be applied in traditional design processes.

Figure.1 “The cripples”of Pieter Brueghel the Elder [5]

A second approach has a much longer and darker history of wars and conflicts. Egyptian stelae and Roman mosaics have shown that technology has been used in rehabilitation contexts since antiquity. The painting “Die Krüppel” of Pieter Brueghel the Elder (Figure.1) illustrates the use of a number of simple tailor-made assistive devices in the 16th century by people with disabling conditions. However, it was World War II that set the stage for modern rehabilitation movement. In the middle of the 20th century rehabilitation engineering and assistive technology emerged to receive the return of thousands of disabled veterans. For the first time surgeons recommended multidisciplinary scientific and engineering endeavors in rehabilitation [6]. Efforts to improve prosthetics and orthotics resulted in a specialty that adopted scientific principles and engineering methodologies. Later on the meaning of disability was redefined as not being intrinsically part of the person, but rather as a function of the interaction with the environment [7]. Organizations were established to address other technological problems of rehabilitation, including communication, mobility and transportation. From that moment on the terminology "assistive technology" (AT) was commonly used to characterize devices for personal use that were particularly created in order to enhance the physical, sensory, and cognitive abilities of people with disabilities and to help them function more independently in environments oblivious to their needs (Story et al, 1998).

1.2. The gap

Though coming from quite different histories and directions, the purpose of universal design and assistive technology is the same: increasing independency, improving the quality of life and reducing the physical and attitudinal barriers between people with and without disabilities. Universal design aspires to address the needs of the widest possible audience in the mainstream whereas assistive technology attempts to meet the specific needs of individuals. Both have from an industrial design point of view more than one opposed characteristic (figure2). Universal design is based on the “economies of scale” principle which involves mass production techniques and traditional design processes. Therefore it homogenizes the abilities of users. It puts the emphasis on providing cost-efficient aids by finding a certain stage of consensus thus it includes as much users as possible.

On the contrary rehabilitation technology always starts with a clear focus on the constraints and possibilities of one unique individual living in a specific environment. It has a culture of trial and error through iterative processes between rehabilitation technologists and occupational therapists. AT products are in most cases produced in small batches due to tailored aspects which makes them almost not affordable without grants. In some cases standard products are used but get physically hacked to satisfy the specific user requirements.

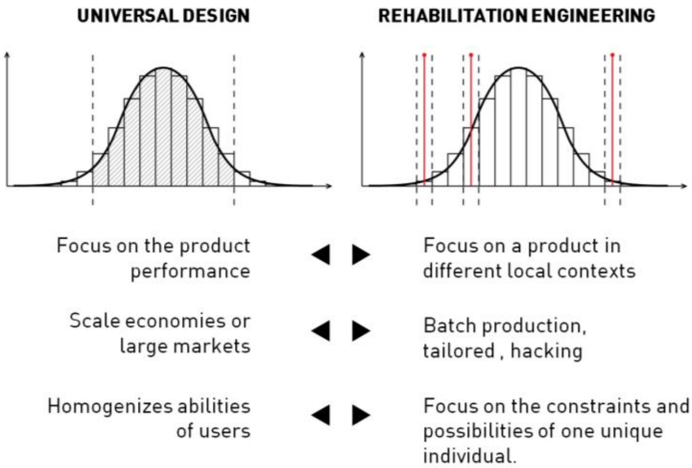

Figure.2 The differences between universal design and AT

As Story et al [8, p11] observed : "*Commercial designers still have a lot to learn from rehabilitation technologists who are familiar with the ergonomics of disability and aging. Rehabilitation technologists and their clients can benefit from a designers' expertise in creating products and environments that are besides functional and safe also attractive, and marketable for a wide diversity of users.*"

Design for (every)[one] aims to close this gap by suggesting some new approaches which are driven by rising social and technological trends. In fact, some products already have enjoyed crossover success, often starting as assistive devices and becoming mainstream products, such as the kitchen utensils with thick grips popularized by Oxo International in their "Good Grips" line. A few products have moved the other way, typically conceived as high-tech devices that find new applications in the rehabilitation arena, such as iPhone apps for disability and vision impairments. Unfortunately the crossover successes are very scarce. This gap became with the laps of time a gray zone in which products and environments are not clearly "universal" or "assistive". They neither fit usability standards or specific user requirements. One could say that both disciplines grew too much towards each other while blurring their specific characteristics which resulted in some kind of identity crisis. Through the industrialization and mass-production culture universal design gained a lot of attention. Excellent work has been done, but the emphasis always has been laid on providing cost-efficient aids and finding a certain stage of consensus so that the maximum number of users are included.

This approach became so strong that it still even influences rehabilitation engineering to this very day on the level of accessibility, availability and affordability. Due to niche markets the diversity and variations of specific assistive devices are very limited. Most of the time rehabilitation technologists use standard assistive products that approximate the users requirements as well as possible. Due to standardization most of the tools also lack esthetical beauty and brand the user with a product stigma**.** In the opposite case, the patient or therapist doesn't use the universal products but takes them as starting points to build his or her own personalized applications.

This traditional approach leads in real terms to very specific healthcare products which are made with high iterative contribution of the end-user. This process becomes very time consuming and is therefore hardly used, due among others to the high technological barriers to overcome. The technique is mainly used for developing unique prostheses and practiced in situations where occupational therapists have the physical tools and technical support to build these products. For daily consumer products that are related for instance to one's leisure, this approach is too costly. And last but not least… Even though good assistive devices are designed they often don't reach the end-user. The interplay between people, practice, politics and economics has created hidden interdependencies and continuously changing requirements which makes the healthcare market very hard to enter. The aim of the this paper is to introduce Design for (every)one and to draw a clear line again between Universal Design and AT. It takes the tailored-made characteristics of rehabilitation engineering even further by introducing a horizontal user innovation network.

2. User innovation

Disabled individuals and paramedics participating in the network, design and build innovative assistive devices for their own use and afterwards they freely reveal their design information to others. Those others then are invited to replicate and improve the device and even to take a share in the innovation process by revealing their improvements in turn – or they may simply replicate the product design and adopt it for their own, in-house use. Eric von Hippel [1] describes this type of open network as a place where "innovation development, production, distribution and consumption networks can be built up horizontally – with actors consisting of only innovation users (more precisely: user/self-manufacturers)." A horizontal user innovation network enables each (disabled) individual to develop the assistive devices according to his or her specific needs. A person is no longer restricted to available marketplace choices nor relies on specific manufacturers.

By applying this open network to the level of rehabilitation engineering (Figure.3) we aim that:

-Individual disabled people benefit directly from solutions that answer their specific problems.

-Manufactures can use this generative design thinking approach to determine what should be designed and sometimes what should not be designed and manufactured as universal design products.

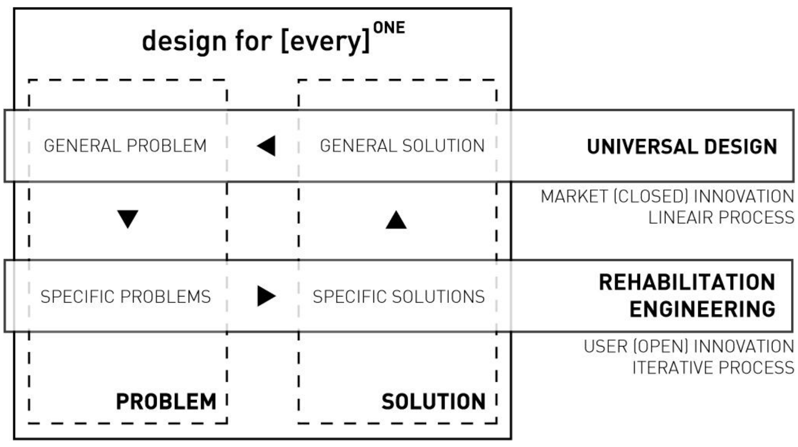

Figure.3 Framework Design for (every)^{one}

It is a system wherein disabled people and their caregivers become conscious actors, rather than being objects of pity and in need of care. Giving them the right tools occupational therapists and their patients can be manufacturer by themselves.

3. Innovation development

3.1. Co-design

The start of this research project (Figure.3) focuses on the innovation development within the level of rehabilitation engineering. Within rehabilitation institutions and assistive technology companies teams still tend to have exclusively clinical and engineering background; the dominant culture is one of problem solving and cost-cutting. Innovation within these fields is mainly technological driven: it lacks the tools to deal with social complexity and emotional responses. Traditional thinking which is embedded in these disciplines follows an orderly and linear 'top down' process (Figure.4), working from the problem towards the solution. Once you have the problem specified and the requirements analyzed, you are ready to formulate a solution, and eventually to implement that solution. This is illustrated by the 'waterfall' line.

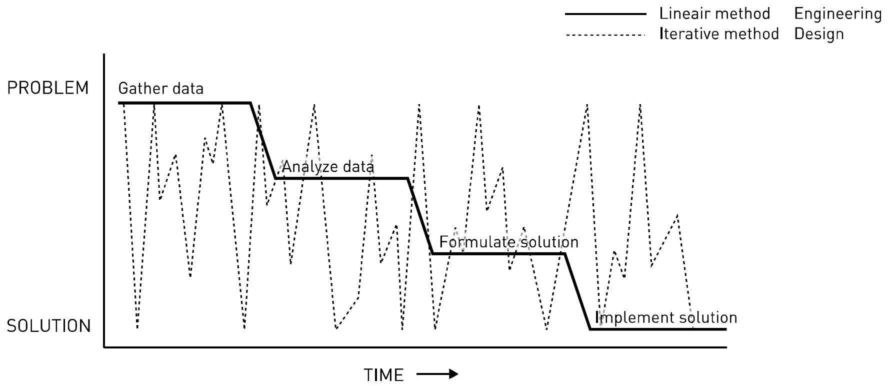

Figure.4 wicked problems Jeff Concklin [9, p9]

Jeff Concklin [9] describes that these linear processes work for tame problems which have a well-defined and stable problem statement. Although these problems can be technically very complex they belong to a class of similar problems which already have been solved in a same similar way.

Nobody will discuss the fact that today's health and welfare landscapes are very mutable and complex systems. The interplay between practice, politics and economics has created hidden interdependencies and changing requirements. On top of that we already mentioned that there is no such thing as an average "disabled person" living in an "average context". The World Health Organization recognizes disability "as a complex interaction between features of a person's body and the features of the environment and society in which he or she lives." Little can be learned by objective data gathering and analysis. Problems involving disabled people have a certain "wicked component" which demands an opportunity-driven approach; requiring decision making, doing experiments, launching pilot programs, testing prototypes, and so on. A certain amount of trial and error is necessary in untangling the physical, emotional and cognitive needs of specific patients. Problem understanding can only come from creating possible solutions, building knowledge through validating specific solutions with individual users [10].

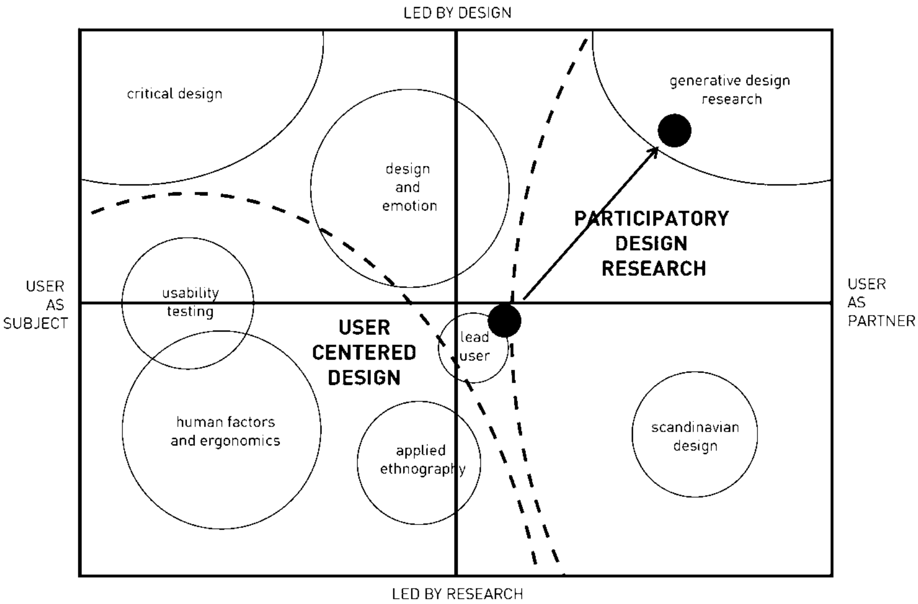

Figure.5 Strategy on the human-centered design research map from Sanders and Stappers [2, p2]

This is the point where co-design methodology comes in as a powerful engine for user-innovation (Figure.5). Co-design can be used as a set of iterative techniques and approaches that puts users at its heart, working from their perspectives, engaging latent perceptions and emotional responses. With the combination of physical prototypes (led by design) it becomes a tangible pragmatic tool which continuously shifts between “what is needed?” and “what can be build?”. This polarity forms the basis of Design for (every)^{one}.

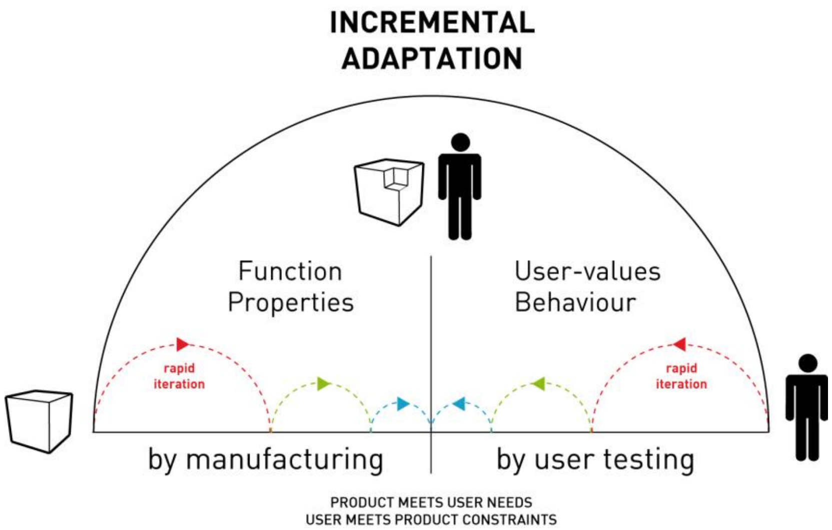

Figure.6 Incremental adaptation, product meets user and visa versa.

Every cycle we gain more insights on both levels. This incremental adaptation process makes use of low-end prototyping techniques for translating user-values into product properties and vice versa (Figure.6) [11]. The main aim is to bring technologies and users incrementally closer and to create applications which support the patient in achieving his personal goal. The point of ideality where a technology and a user meet 100% will rarely be reached as users are moving targets with ever changing requirements. In a way, products are never finished. A new way to think about design is seeing it as an infinite process that stimulates continuous innovation and adapts to people within continuously changing contexts.

3.2 The key-roles

The key-roles in this co-design process are forming a trialogue around the aspects of assistive technology: goal, technology and user (Figure.7). We rather talk about archetypal roles than actual key-players because in some situations certain actors could be filled in by the same physical person simultaneously. A caregiver could fulfill the role of self-manufacturer, an occupational therapist is in some cases the patient or a self-manufacturer is in the meanwhile occupational therapist. It is important to notice that there are 3 roles with different perspectives and each of them needs to pick up the problem with a different attitude.

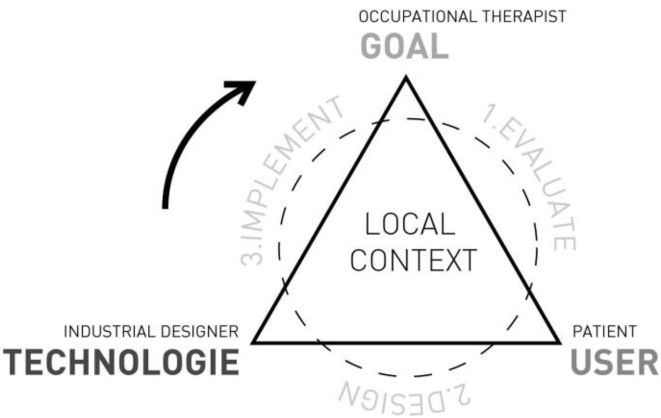

Figure.7 Trialogue between key-roles and iterative actions.

(1) GOAL : Paramedic/occupational therapist:

The occupational therapist keeps the overall goal of AT in mind: increasing independency and improving the quality of life. With his clinical background he sketches the medical constraints and possibilities for each individual patient. Designing this personal assistive device is like handing over a birthday present. The better you know your patient the better you know what to buy. Researchers at the University of Toronto's Quality of Life Research Unit define quality of life as “The degree to which a person enjoys the important possibilities of his or her life”. Their Quality of Life Model is based upon the categories “being”, “belonging”, and “becoming” - respectively, who one is, how one is connected to one's environment, and whether one achieves one's personal goals, hopes, and aspirations. Besides mapping the medical constraints this exercise is also carried out on the patient and on the caregivers in his environment.

The occupational therapist detects which type of assistive device the patient needs to achieve his or her goals and by doing so he sets the starting point for the first iterations. In most cases the patient and therapist have already physically hacked an universal assistive device which can be seen as a translation of a latent need or a hidden solution for the problem. The therapist evaluates every iteration through the behavior of the patient.

(2) USER: Patient/Caregiver

The patient is given the position of 'expert of his/her experience'[12]. In some cases when the patient has difficulty with communicating his feedback verbally, the caretaker plays an important role as translator. Depending on the level of creativity they join the design process by expressing themselves in creating, using or adapting the assistive prototypes. Due to the iterative character of the methodology it is important that patients are mentally capable of building on past user experiences. The perceived value of a product is critical and determines the strategy of the following iterations. While reducing or eliminating the negative experiences and enhancing more positive values, the patient also slowly adapts to his new assistive device.

Although the nature of an everyday task could look simple, the context in which it takes place is always characterized by intricate interaction patterns between the user, his assistive appliance and the environment. Next to all the user experiences we try to map all these interactions in a user-product-environment model. Who are the stakeholders? What are their requirements? Without being included in the thinking and decision-making process, certain stakeholders may seek to undermine or even sabotage the project.

(3) TECHNOLOGY: Industrial designer/user-manufacturer

The industrial designer becomes the facilitator between the occupational therapist and the patient. He continuously translates user-values and behavior into product properties. His main job is to ideate and create tools/prototypes, which enables the occupational therapist to communicate on a physical level with his patient. In some "in vivo" test cases it is difficult to obtain full-time engagement because the patient is sometimes too fatigued or in pain to complete the user testing. Time is precious, so therefore we have to plan a scenario for each user-testing activity and avoid the fact that we may overload the patient with too much information. The more varying and pronounced the concepts are, the quicker we get converging feedback from the user. When evaluating concepts, it is important to strive for the highest "level of measurement" by means of discovering the different aspects that are relevant for the user. In most cases aspects of iterated concepts will be perceived as "better", "good enough" or "worse" than the previous iterations. It is task of the industrial designer to document this process and leave as many traces so that the user-community can harness the lessons learnt from the project.

The key language in this methodology is composed of physical prototypes. The user-manufacturer has to be creative with the resources at hand, which leads in most cases up to a form of "hacking design". Product concepts are build and adapted out of re-used devices and basic materials which are available in the local context. Hacking methodologies have been particularly useful in developing nations for increasing the functionality of mobile phones and deploying the bicycle to serve other needs. But they are equally useful to address the needs of disabled people in Western culture as well.

During this process the user-manufacturer slowly shifts from experience prototyping to personal manufacturing. He keeps a track of existing, new and emerging technologies, has an overview of available production processes. The design of the assistive devices should result in "open products" under creative commons licenses [13] which other occupational therapists can build on and apply in various rehabilitation contexts. Like open source software there is no ending point and products become tangible versions of human needs. This process of hackufacturing, as Scott Brunham [14] is calling it, could be the next step in the physical read-write culture of tomorrow. The intellectual property of the source design remains with the designer while the alteration and realization of the final product anchor it in the resources and realities of a local manufacturer.

3.3. Adaptation strategies

At the beginning of each process a clear status has to be sketched as a reference point. Sharing models at this early stage sets the basis for understanding, agreement, and action. That’s why we use a comprehensive and yet manageable set of adaptation strategies which guide the key-players in the complexity of perceived value. This semi-structured framework is based on the user-value adaptation theory of Suzan Boztepe [15] and exits out of 5 main strategies (Figure.8) : performance, economy , convenience, identity and pleasure adaptation. Each strategy highlights a range of specific aspects which could play a relevant role in certain contexts.

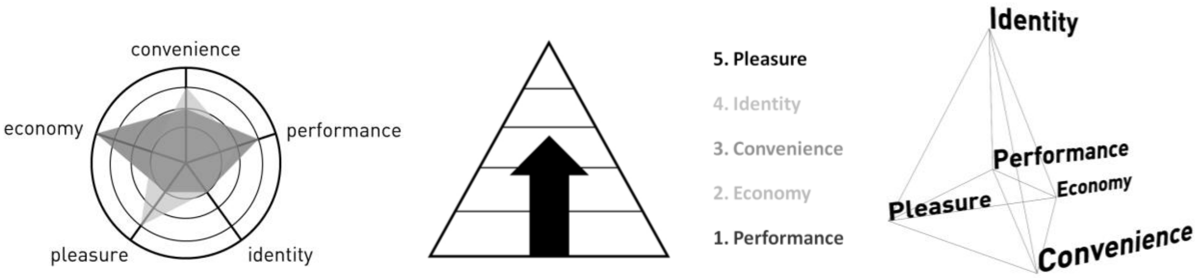

Figure.8 mapping the status of the assitive device and setting the adaptation strategy

• Performance adaptation: Functionality, Efficiency, Durability, Safety, Time Management, Usefulness, Maintaining/Repairing,…

• Economy adaptation: Number of parts, Number of functionalities, Type of production process, Type of Materials, Type of connections, Accessibility of local resources,…

• Convenience adaptation: Physical and cognitive aspects, Activities surrounding the product, Interface/Feedback, Behavior/Habits, Usability/Compatibility,…

• Identity adaptation: De-stigmatization, Customization/Personalization, embedding Cultural aspects, Product Personality/Visual meanings, Group Belongings/Role fulfillment,…

• Pleasure adaptation: Playfulness/Gaming, Motivation/Persuasion, Sentimentality, Creativity, Experience/Use of senses,…

Based on the feedback of the patient an overall certain strategy is set to guide the process. A second goal of this framework is to strengthen the analysis of field data and to produce intelligent conclusions that extend far beyond predictable outcomes. Although we design and implement adaptations according to a linear strategy, the user always experiences these 5 main aspects simultaneously (Figure.8). It is important not to avoid side-remarks, but to use them as thick descriptions in the right strategy adaptation. The aim of the key-players is to find the pattern between these aspects and build a model which describes the relevant relationships.

4. Practical applications

Figure.9 Karla “guitar slider”, Korneel “badminton shuttle”, Sebastian “Icecream ring”

The guitar slider (Figure.9) was designed with Carla. She suffers from hemiplegia, a condition in which the limbs on one side of the body have severe weakness. Her passion is playing the guitar and together with her occupational therapist she developed an assistive appliance which enables her to achieve this goal. The original object reflects that the principle of sliding is a possible solution for her specific requirements. This “hidden solution” was the a starting point of two co-design iterations with an industrial designer. The output is a DIY assistive appliance build to professional standards. Some parts are universal other are quiet specific but can be produced with the help rapid manufacturing techniques such as 3D-printing. The strategy in this case was set on performance, economy and convenience.

The next object involves Korneel passion for playing badminton (Figure.9). Unfortunately, he has severe problems to return the shuttle to his opponent. Korneel has problems with his hand/eye coordination and is slow in estimating game tactics. He doesn’t want to cheat on the playing rules of badminton? In first brainstorms, several shape variations of the racket and shuttle were made. Out of these experiments with the patient, altering the shuttle was the better solution. The shuttle was deformed and colored, so that the shuttle makes a spinning movement and slows down doing so. This gives Korneel the opportunity to correct his movements and to return the shuttle several times. The strategy in this case was set on performance, pleasure and convenience.

The last object is an ice-cream aid (Figure.9) designed with Sebastian. During a serious accident Sebastian broke some spines and became paralyzed. He transports himself in a wheelchair and one of his favorite all-time activities is eating a certain type of ice cream. Due to his accident the user has not enough strength to grasp the thin ice-cream stick. He tried already some standard existing solutions but all of them were in his opinion very unpractical and stigmatizing. During a co-creation session the prototype of ring with a small clip inside awoke a lot of reactions : *“ I would even wear it continuously as a nice piece of jewelry... and still be able to steer my wheelchair while eating…*”. The strategy in this case was set on performance, identity and convenience.

In all of these trialogues the industrial designer and occupational therapist have been challenging the patient with new appliances build with available resources in his local environment. The only communication tool between all the team members are physical prototypes guide by a certain adaptation strategy. With this approach explicit and latent needs arise very quickly to the surface and guide the design process. Another human aspect that we have been noticing while performing some case studies is the increasing level of commitment that can be reached by including the disabled users in the design process. In the course of the co-creation process they reveal themselves as real ambassadors of their personal assistive devices. Suddenly the device becomes a part of themselves which reduces the stigmatization and augments the product affinity between the patient and his or her assistive tool.

5. Conclusion

Today there are people with disabilities whose assistive devices have not yet come about. In a certain sense we have a moral obligation to ensure that the genius of every disabled person has to express oneself entirely. Due to the demographic shift this group of people is rapidly growing. The key issue will not be the provision of more paramedics and designers, needed though they may be, but how effectively people are engaged in the responsible, collaborative maintenance of their own health. This is not an anti-professional stance; merely an acknowledgement that there is more design opportunity in the world – a greater volume and variety of problems to be solved – than will ever be addressed by professional designers alone. Conditions to apply horizontal user innovation networks in the world of disabilities exist today and will even augment due to technological advance. In this paper we have tried to sketch the holistic framework which starts with the innovation development and the co-creation process between different disciplines.

6. Discussion

Future research will focus on the production, distribution and consumption side of this potential horizontal user network. The aim is to make the tools and services for each stage which stimulate relationships that allow people to collaborate, share ideas and produce their own assistive devices together. The challenge will be to give users the perception of simplicity in accomplishing different tasks within the network. By reducing aspects such as time, cost, physical effort, non-routine, social deviance and brain cycles... toolkits could augment the degree of persuasiveness and stimulate more users in creating and sharing their assistive devices. By making a shift from lead-user research to generative design research we create an open pool of user-innovations that reflect several physical, emotional and cognitive needs. New patterns could be defined and translated in universal design principles that companies can apply in their design processes. These universal principles are in their manner the basis for new creative innovations within the world of mass-production.

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