

The usage of scenarios in the search for innovation regarding the model of rare disease associations: an empirical experience and its findings

Gustavo Berwanger Bittencourt ^a * | Karine de Mello Freire ^a

^a UNISINOS (University of Vale do Rio dos Sinos), Postgraduate Design Program, Porto Alegre, Brazil

* Corresponding author: gbittencourt@unisinis.br

ABSTRACT

Considering the challenge of organizational innovation in the rare disease associations, we propose the usage of Design Orienting Scenarios under the scope of a Strategic Design project. Such empirical experience generates reflections on the usage of scenarios for it stimulates both the participation of actors involved with the strategy and the expression of their visions and potentialities in a broad and democratic sense.

Keywords: Innovation, Rare Diseases, Scenarios, Strategic Design.

1. CONTEXT

In Brazil, there are approximately 13 million people with rare diseases – those which affect up to 65 in every 1.000.000 individuals of a given population (BRASIL, 2014). Whoever has one of these conditions, in most cases, depends upon a continuous treatment either to survive or to live a minimally dignified life. Besides, these people face obstacles such as social exclusion, lack of time and space for private and family life, lack of domestic, psychological, and financial support, in addition to the lack of information about how to treat and deal with the disease and its subjective and social effects (SANTOS LUZ; SILVA; DEMONTIGNY, 2016). This context encourages a search for answers that combines sparse medical orientations with information exchange inside peer support groups (SANTOS LUZ; SILVA; DEMONTIGNY, 2016). It is common that these groups emerge through direct articulation of mothers, fathers and caretakes (MUOTRY, 2007; TUDELA; RAMÍREZ, HENAO, 2018) and end up becoming "rare diseases associations", a terminology which covers a wide variety of formats regarding these organizations (PEREIRA, 2015).

According to Barbosa and Portugal (2018), the rare disease associations usually follow the so-called Utility Model of Care. Such model is characterized by being based on treatments with medicaments developed by the pharmaceutical industry, an objective which ends up concentrating most resources from laboratories, research centers, governments, and the associations themselves. Even though the lives of many people with rare diseases depend, in fact, on these medicaments, other factors, such as citizen participation and multidisciplinary treatments end up being forgotten in this model of association. For Barbosa and Portugal (2018), the overcoming of the Utility Model of Care requires a broader look upon people with rare diseases, and this perspective implies the construction of new forms of associativism. In other words, the model must be rearranged.

Therefore, this article presents a methodological proposal to explore the possibilities of alternative models for this type of organization. Such proposal is based on Strategic Design as understood by certain authors and considers Design Orienting Scenarios as a fertile method for processes of organizational innovation under this scope.

2. ON STRATEGIC DESIGN

Strategic Design as understood by Mauri (1996), Meroni (2008), Zurlo (2010), Franzato et al (2015), Franzato and Campelo (2017), Freire (2017) and Manzini (2017) considers the formulation of organizational strategies as a collective project that takes into account the points of view of the multiple actors involved in multiple relations, fluxes, and processes that shape an organization, seeing that these elements define an organization much more than its formal legal or administrative limits. It is considered fundamental, through this perspective, that everyone who participates in these relations, fluxes, and processes must have a voice in the design of strategy, under penalty of it not building value to the ecosystem, and therefore showing itself to be irrelevant.

This emphasis Strategic Design puts in dialogue and participation as fundamental to the project of strategies: if it is the role of design to serve as transdisciplinary platform that allows different actors involved with the organization to converge (FRANZATO et al, 2015), how is this convergence proposed and operated? How are the different worldviews and project capacities equalized or combined to allow a more equitable participation? A possible answer is the usage of Design Orienting Scenarios.

3. DESIGN ORIENTING SCENARIOS

Manzini and Jégou (2006) observe that there are many methodologies for scenario building but they propose that design has its own form of building scenarios, destined to be used "in the beginning of the innovation process to start it in a coherent and organized manner without reducing the creative interaction necessary to build shared visions". (MANZINI; JÉGOU; MERONI, 2009, p. 18).

Since they are an activity in design themselves (MANZINI; JÉGOU, 2006), scenario building uses, in its process, visualization tools such as collages, storyboards, diagrams and mockups, which facilitate dialogue, understanding, and the choice of paths (MANZINI, 2017). For Manzini (2003), one of the biggest obstacles communities face in order to move towards better futures is precisely the difficulty in finding dialogue processes that help establishing bases and building shared visions of what these better futures would be like, and Design Orienting Scenarios could make this task easier.

Prototyping "as if the world would...", one of the central activities of Design Orienting Scenarios, requests the people involved in the project to leave the concrete level of their day-to-day and to visually and materially imagine other possibilities to create or express positions and, later, to make decisions. Jégou et al (2013) call this "Visual Deliberation" and defend that his approach makes the project process more democratic since it reduces the obstacles to participation and allows interference in the project even when its goal is the discussion and reflection and not necessarily immediate execution.

Another characteristic of using scenarios such as the ones hereby understood is related to their divergent character when they propose, as a result, a multiplicity of possible scenarios

instead of a singular, correct, and unequivocal path. (MANZINI; JÉGOU, 2006). For Reyes (2015), the process of scenario building induces an opening which allows the different actors touched by the project to have their interests represented, amplifying the possibilities instead of trying to synthesize them beforehand. According to the author, it is in the confrontation between these different possibilities that lies the true value of using scenarios in the project as well as its applicability to situations that combine multiple voices. Without this divergent character, the social dialogue promoted by scenarios would be compromised or interdicted (MANZINI, 2017), losing one of its most crucial functions, reducing even its innovative potentiality.

Meroni (2008) stresses that scenario building, because of its capacity to translate information and intuitions into perceptible, shareable, and debatable knowledge, is the manner through which the strategic designer addresses their problems.

4. AN EMPIRICAL EXPERIENCE

The empirical experience in which this article is grounded is part of a Strategic Design process that took place between July and October 2019 during a master's degree research. One of the moments of such process included a design workshop with the participation of families and health and education professionals involved with children diagnosed with Prader-Willi Syndrome, a random genetic disfunction that causes a series of symptoms in different intensities depending on genetics, the measure of clinical intervention and the social environment in which the affected person lives. Among the most common symptoms, there is the delay of motor and cognitive development, learning disabilities, mood swings, and a specific interest for food that may become an obsession (MESQUITA et al., 2010). The main goal of the workshop was to create a new model of rare diseases associations, which was done through a series of co-design activities among which there was one related to dialogue, construction, and alignment of visions of well-being of the children with Prader-Willi Syndrome.

In this activity, the scenario building was made in a mockup format. From a prospective assignment (Figure 1), the participants were divided in two groups of three, and each trio received a bag with toys and other children's objects.

ACTIVITY 2

With our capabilities, we want to build a situation, a condition, a future of well-being for our children, patients and students. But what do we mean by well-being? What is our vision of well-being?

Bittencourt, G. B. & Freire, K. M. (2021). The usage of scenarios in the search for innovation regarding the model of rare disease associations: an empirical experience and its findings. *Strategic Design Research Journal*. Volume 14, number 03, September – December 2021. 508-515. DOI: 10.4013/sdrj.2021.143.05

Figure 1. Slide with the activity presentation.

The task consisted in building, with the toys, an ideal and future scenario of well-being that welcomed the sons/daughters/patients/students of the participants (Figures 2 and 3). After

A photograph of a miniature diorama on a wooden table. The scene includes a globe, a red pen, a small airplane, a green power drill, a pink piggy bank, and several small figurines. In the background, there are cardboard cutouts of buildings labeled 'SILVIO', 'Oficina Mecânica', and 'GAS-OLEO'. A book titled 'COMO SER UM ESPÃO' is visible on the left.

page 511



Figure 5. Group presenting and debating the scenarios.

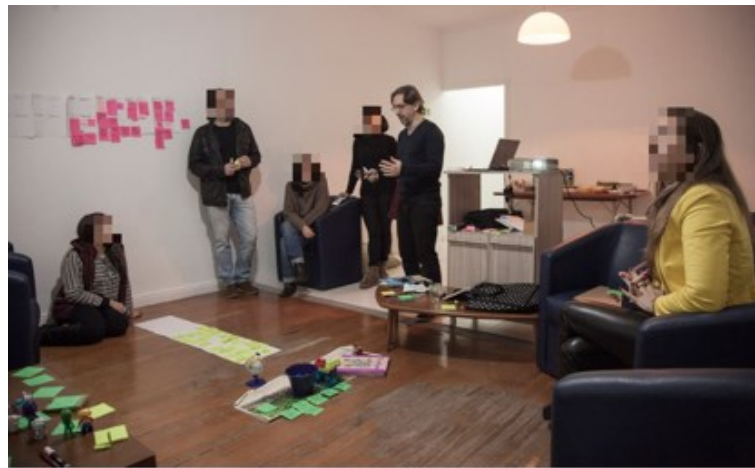


Figure 6. Ideas connecting the capacities to the scenarios.

5. RESULTS AND DISCUSSION

The analysis of the materials produced during the field research demonstrates the strength and fertility of the usage of Design Orienting Scenarios as part of a Strategic Design process. The participants presented recurrent behaviours and arguments that denoted creative and reflexive force of the manipulation and resignification of physical supplies (such as books and toys) configured in scenarios - as Figures 2, 5, 6 and 7 demonstrate as well as the transcribed audio clips below:

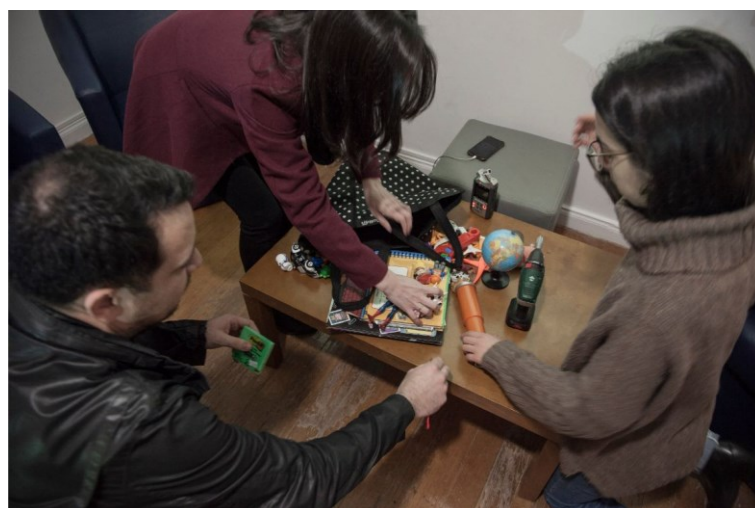


Figure 7. Participants building a scenario and deliberating.

"I thought of the globe and this telescope about the discoveries, you know. About what he will, what he needs to have access to discoveries, like this, you know?" (FATHER)

"This, I don't know what it is... to provide discoveries. Experimentations. I think it's important to put safety and overprotection, so we can look at these two aspects, to find a fine line between the two things. It was mostly this, right, experimenting, things we think are dangerous for the children but I think we need to provide them, I think it fits in here." (EDUCATOR)

"It is the broadening of horizons, of places in the world, to know they can invent things. Mechanics gave me a lot this question of creation, of creating new things, new tools." (EDUCATOR)

"I am going to put a different Figure. Let's put in here [...] the question of borders." (DOCTOR)

The participants made a series of inferences from physical supplies provided in the activities.

"I think the Little Prince (book) is not here on a coincidence. This thing about looking at other universes. The world and the plane are also about that, right." (EDUCATOR)

They have also brought creative experiences outside of the workshop that connected to creative activities in the workshop:

"My 4-year-old daughter, she loves experimenting. She found out about this pencil that you wet it and can make a tattoo, she loved it." (FATHER)

As a first consideration, we emphasize that, in many moments, the usage of graphic and material resources configured into scenarios allowed the participants to create relations between individual ideas and build combinations. What could be observed, in other words, was the concept of Visual Deliberation (Jégou et al, 2013) in action: the possibility to project futures and think more creatively and collectively, stimulated by the conjunction of the scenario proposal with the support of everyday graphic and material resources dislocated from their common function.

A second point to highlight is the high involvement of both groups with the activity, to which we partly credit to the choice of using an open format of scenarios, not linked to any specific conceptual model. It was asked to the group that, from the objects and with the help post-it notes, they created "scenarios of well-being". The simplicity of the instruction allowed the groups to feel comfortable to express themselves in their own understanding without the need to be in conformity with any type of formal structure of Design Orienting Scenarios.

The third relevant point to be made is the fact that the activity of building scenarios of well-being provided the creation of two different proposals and the comparison between its similarities and divergencies, which allowed the group to see collectively in its aspirations and verify that consensus and dissensus were present. From this evocation, the group could create a temporary synthesis of their proposals so that the workshop would progress to the following step of ideation of solutions – but only after this visual deliberation and of high strategic power.

6. FINAL CONSIDERATIONS

It was proposed here that Strategic Design, as understood by the consulted authors, has predicates that allow it to offer methods and tools more aligned with the aspirations of groups

of citizens who seek to innovate collectively in environments filled with socio-economic difficulties – such as the one with people who create rare diseases associations. Among these methods, there is Design Orienting Scenarios. When proposed and operated through Strategic Design, as we have discussed, this Scenarios emerge as an important moment in an innovation process of organizational model, for it allows the broadest and deepest expression of the necessities and potentialities of groups who seek or need to orient themselves through more holistic, democratic, and sustainable visions of well-being. In the case of rare disease associations, this means going beyond the Utility Model of Care.

The orientation to innovation, to visuality, to prototyping and to active participation enables the usage of Design Orienting Scenarios as a method that offers resources to non-designers so they can perform, in an assisted way, the level dislodgment that designers usually perform more naturally. (FRANZATO, 2014). Ludic tools of visualization, manipulation, and narration, that compose a process of prototyping in the form of visions, motivations, and proposals, induce non-designers to leave, even if momentarily, their everyday place and raise them (or their dialogues) to a superior level of understanding and project creation even if they do not have any conscience of this movement.

Considering the above, we believe that Design Orienting Scenarios contribute to the construction of a culture of life projects born from collective conversations and significant interpersonal relations in contrast to isolation and merely transactional relations (MANZINI, 2019), that are usually the main goal of management culture methodologies, still the most influential when discussing innovation in organizational models.

REFERENCES

- Barbosa, R.L., Portugal, S. (2018). *O associativismo faz bem à saúde? O caso das doenças raras* [Is associativism good for health? The case of rare diseases]. *Ciência & Saúde Coletiva*. 23(2). DOI: [10.1590/141381232018232.24032017](https://doi.org/10.1590/141381232018232.24032017).
- Brasil. Ministério da Saúde. Portaria nº 199, 30 de janeiro de 2014. Brasília, DF: *Ministério da Saúde*, 2014. Retrieved March 24, 2019, from http://bvsms.saude.gov.br/bvs/saudelegis/gm/2014/prt019930_01_2014.html.
- Franzato, C., Campelo, F. (2017). Special issue: strategic design research journal tenth volume. *Strategic Design Research Journal*. 10(2). DOI: [10.4013/14619](https://doi.org/10.4013/14619).
- Franzato, C., Del Gaudio, C., Parode, F., Borba, G., Freire, K., Bentz, I. (2015). *Inovação cultural e social: design estratégico e ecossistemas criativos* [Cultural and social innovation: strategic design and creative ecosystems]. In: K. Freire (Ed.), *Design estratégico para a inovação social e cultural* (pp. 157-182). São Paulo, Brazil: Kazuá.
- Franzato, C. (2014) *O princípio de deslocamento na base do metadesign* [The principle of displacement at the basis of metadesign]. In: *Proceedings of 11º Congresso Brasileiro de Pesquisa e Desenvolvimento em Design* (pp. 1187-1196). São Paulo, Brazil: Blucher. Retrieved July 30, 2019 from http://www.ufrgs.br/ped2014/trabalhos/trabalhos/178_arq2.pdf.
- Freire, K. (2015). *Design estratégico para inovação social* [Strategic design for social innovation]. In: K. Freire (Ed.), *Design estratégico para a inovação social e cultural* (pp. 13-41). São Paulo, Brazil: Kazuá.
- Freire, K. (2017). From strategic planning to the designing of strategies: a change in favor of strategic design. *Strategic Design Research Journal*. 10(2). DOI: [10.4013/sdrj.2017.102.01](https://doi.org/10.4013/sdrj.2017.102.01).
- Jégou, F., Delétraz, C., Massoni, G., Roussat, J., Coirié, M. (2013). Acupuncture Planning by Design. In: E. Manzini, E. Staszowski (Eds.). *Public and Collaborative. Exploring the intersection of design, social Innovation and Public Policy* (pp 139-153). New York, US: Desis Network.
- Manzini, E. (2017). *Design quando todos fazem design: uma introdução ao design para a inovação social* [Design When Everybody Designs: An Introduction to Design for Social Innovation]. São Leopoldo, Brazil: Unisinos.
- Manzini, E. (2019). *Politics of the everyday*. London, UK: Bloomsbury.

- Mauri, F. (1996). *Progettare progettando strategia* [Design by designing strategy]. Milano, Italy: Masson S.p.A.
- Manzini, E., Jégou, F. (2006). Design Degli Scenari. In: P. Bertola, E. Manzini (Eds.), *Design Multiverso. Appunti di fenomenologia del design* (pp. 189-207). Milano, Italy: Edizioni POLI.design.
- Manzini, E., Jégou, F., Meroni, A. (2009). Design oriented scenarios: generating new shared visions of sustainable product service systems. In: M. Crul, J.C. Diehl, R. Chris (Eds), *Design for Sustainability (D4S): a step-by-step approach* (pp. 15-32). Delft, Netherlands: United Nations Environment Program (UNEP). Retrieved July 18, 2019 from <http://www.d4s-sbs.org/MB.pdf>.
- Manzini, E. (2003). Scenarios of sustainable wellbeing. *Design philosophy papers*, 1(1). DOI: [10.2752/144871303X13965299301434](https://doi.org/10.2752/144871303X13965299301434).
- Meroni, A; Fassi, D; Simeone, G. (2013). Design for Social Innovation as a form of design activism: an action format. In: *Proceedings from SOCIAL FRONTIERS: the next edge of social innovation research conference*. London, UK: Nesta. Retrieved May 19, 2019 from https://www.researchgate.net/publication/263016635_Design_for_Social_Innovation_as_a_form_of_Design_Activism_An_action_format.
- Meroni, A. (2008). Strategic design: where are we now: reflection around the foundations of a recent discipline. *Strategic Design Research Journal*. 1(1). DOI: [10.4013/5567](https://doi.org/10.4013/5567).
- Mesquita, M.L.G., Brunoni, D., Pina Neto, J.M., Kim, C.A, Melo, M.H.S., Teixeira, M.C. T. V., (2010). Fenótipo comportamental de crianças e adolescentes com síndrome de Prader-Willi [Behavioral phenotype of children and adolescents with Prader-Willi syndrome]. *Revista Paulista de Pediatria* (pp 63-69). 28(1). DOI: [10.1590/S0103-05822010000100011](https://doi.org/10.1590/S0103-05822010000100011).
- Muotry, A. (2007, September 7). *Associações de pais e pacientes* [Parent and Patient Associations]. Retrieved March 24, 2019, from <http://g1.globo.com/platb/espisal/2007/09/07/associacoes-de-pais-e-pacientes/>.
- Pereira, C.C.Q.P. (2015). *Sobre a participação das associações de pacientes na construção do conhecimento sobre saúde: o caso das doenças raras* [On the participation of patient associations in the construction of knowledge about health: the case of rare diseases]. (Doctoral dissertation). Pontifícia Universidade Católica de São Paulo, Brazil.
- Reyes, P. (2015). *Projeto por cenários: o território em foco* [Project by scenarios: the territory in focus]. Porto Alegre, Brazil: Sulina.
- Santos Luz, G., Silva, M.R.S., Demontigny, F. (2016) Priority needs referred by families of rare disease patients. *Texto & Contexto: enfermagem*, 25 (4). DOI: [10.1590/0104-07072016000590015](https://doi.org/10.1590/0104-07072016000590015).
- Tudela, J.C., Ramírez, G.P., Henao, A.M. (2018). *Do movimiento asociativo de las enfermedades raras en Iberoamérica* [The associative movement of rare diseases in Latin America]. Murcia: Alianza Iberoamericana de Enfermedades Raras o Poco Frecuentes.
- Zurlo, F. *Design strategico* [Strategic Design]. (2010) Roma: Enciclopedia Treccani, 4. Retrieved March 24, 2019, from http://www.treccani.it/enciclopedia/designstrategico_%28XXI-Secolo%29/.