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THE ADAPTIVE DESIGN TRIAD

CO-CREATION REQUIRES HUMILITY & SELF REFLECTION

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PAPER ABSTRACT:

Raymond Lowey once said, ‘Design is too important to be left to designers’. As an industrial designer and educator trained in the 1980’s, and with over 25yrs experience in the classroom, I can attest to the fact that all these years later designers are still taught to be the lone creative genius. Of course, they are encouraged to research and talk to experts and users and inform their designs with knowledge beyond their own, and some of them work in multidisciplinary teams, but the creative act is jealously guarded as being the sole prerogative of the designer.
In this letter I will lay out an alternative way of designing, one in which the creative effort is shared and owned by a group of stakeholders with differing and essential perspectives on the needs to be addressed. This letter will focus in particular on how designers co-create with people with disabilities and clinicians to produce Adaptive Designs that meet the custom needs of an individual co-creation partner. Collaborative design (co-design) or co-creation is not a new concept. However, I suggest that there is an opportunity to more deeply ground theories of equitable co-creation in immersive engagement with people with disabilities as key partners in the design process. .

Keywords: Co-design, Adaptive design, Participatory Design.

1. INTRODUCTION

This alternative way of designing is centered on the core-principle that the creative effort has to be shared and owned by a group of stakeholders with differing and essential perspectives on the needs to be addressed. In essence, the approach fits under the broad umbrella of Co-design, which has a long and storied history stretching back to the early 1970s in Northern Europe (Sanders ,E. B.-N & Stappers,P.J. 2008 p5). The idea of co-design or co-creation is a commonly used term in design practice and particularly in education, but the practical implications of doing the work, intervening in a given context with a group of people, is so often shrouded in vague descriptions based on short-term interactions with ‘users’. This framing of the co-design partners as ‘users’ or even ‘expert users’ is particularly problematic because by definition it ‘others’ the person cast in this role, placing them in a hierarchical relationship to receive and use the product of the co-design work.

Much is talked about the *what* of these practices, in particular, what 'change' resulted from these collaborations. However, based on my analysis and experience of research and practice to date, too little focus is placed on the *how* of such design approaches. How can we ensure that such design collaborations meet the self-identified needs of the people we are working with? How can we center their perspectives and expertise in the creative process? How can we build reflective practice into our work together so that we constantly check the equity of input as well as doing the work of self-reflection to check our own bias and ego?

Current approaches to co-design do little to challenge the role of the designer as the sole creative genius on the team, or the final arbiter of what is 'good' design. One might say, what's wrong with this? In a multi-disciplinary team surely we all must play to our strengths and a designer's strengths lie in designing? To answer this I will take a brief diversion into my experience as a designer and researcher in contexts other than western capitalist consumerism. Early in my journey into exploring how to define and shape equitable co-creation processes, I spent over a decade researching how designers engage with what I term 'development contexts'[1] (Fathers, J. 2012). In my search for guidance on how to engage in this area, which included immersive 'grass-roots' research with craftspeople in South East Asia, Participatory Development Theory emerged as a key framework for working with people. I found this particularly helpful because early in my study it became very clear that the discipline of design at that time had few if any frameworks for non-hierarchical, equitable, sustainable engagement with people and their environments. As I reflect on the role of design practice in today's contexts, more than ever it is essential that design and designers adopt a code of practice in working with others, to ensure that the outcome of the process is focused on the real and felt needs of the recipients or users, rather than those prescribed by others. In this practice it is essential that expertise of all types, especially the expertise of experience, has an equal say in the development of the end product or system.

2. ADAPTIVE DESIGN

So what is Adaptive Design? [2] Developed during the 1980's as a local, low-tech response to meeting the needs of individual people with disabilities, the Adaptive Design Association (ADA) is one of the earliest innovators in this field: "We create custom adaptive equipment to maintain or improve the functional capabilities of children and adults with disabilities" (Adaptive Design Association, 2023). Based in Manhattan, New York, ADA has been transforming the lives of individuals with disabilities by designing and producing innovative, low-cost adaptive devices for over twenty years. One of the key people and key thinkers and innovators in this field is Alex Truesdell. She founded the ADA in 2001 after more than

[1] Development contexts are those situations and circumstances where there is a need for development, where the 'need' is defined by those immersed in the context (not prescribed from outside) and where development is defined as Good Change (Chambers 1997 p xiv).

[2] Adaptive Design: In this paper I am referring to AD as the practice of designing devices for with people with disabilities. The term is also used for very different practices in other fields such as UX/UI design.

20 years developing and refining these techniques at the 'Perkins School for the Blind' in Boston, Massachusetts. In 2015, the MacArthur foundation recognized her innovative approach to solving critical global problems by awarding Alex with a MacArthur Fellowship.

In a recent discussion with Alex, she described to me the driving force behind her passion for Adaptive Design,

> "If you are declared disabled and don't have a team of advocates, your cognition is likely to be doubted, and health, education, and vocational systems will probably not expect you to achieve more than 'di minimis' progress…the vast majority of people with disabilities are far more capable, and far less limited, than their paperwork and services suggest." (A. Truesdell, Personal communication April 10th 2021).

2.1 THE ADAPTIVE DESIGN TRIAD

What is the Adaptive Design Triad? At its most simple it is a co-creative relationship between designers, clinicians and people with disabilities. The principle, well-established in the disability community of 'Nothing about us without us is for us', is at the core of this creative relationship (Charlton,J I. 1998 p3). The deep, experiential expertise of the person with disabilities and their family/carers/advocates is centred, augmented and informed by the expertise of the clinician (doctor, occupational therapist or physical therapist) or that of the designer. Why three types of input, three types of experts, why a triad? Because tripods and three legged stools are the most stable on an uneven surface and because from a research viewpoint, 'triangulation', or supporting a hypothesis with data from three separate sources, is the best way to draw reliable conclusions. So with the goal in mind to produce designs that are 'reliable' and 'stable', how does this work out in practice? - because many theories look very impressive until they are tested in the crucible of real life. This approach has been developed, tested and refined in participatory design projects over the past seven years following a methodology of participatory action research.

In the following images (Figures 1-7) the Adaptive Design process is illustrated. In this case, the Triad consists of Mum & Alley (name changed) an Occupational Therapist (OT) and myself as a designer.[3] Alley is keen to be more independent and help her Mum around the house. She has very good arm strength but less strength in her legs. She expressed the need/desire for some steps so that she could: be able to reach the sink to help wash up and prepare food; wash her face and clean her own teeth; get in her wheelchair or on the sofa etc. It important to note here that this expression of need/desire,

[3] This interaction took place over one intense weekend. Nowadays because the adaptive design work in Syracuse is more established, relationships and design interventions have more time to develop we have a local Adaptive Design workshop: Arise adaptive design co-founded by the author in partnership with local people with disabilities, clinicians & designers (https://arisead.wordpress.com - https://www.ariseinc.org/services/adaptive-design/). In addition to elective classes taking place in the School of Design at Syracuse University - Adaptive Design DES400/600.

flowed out of an ongoing clinical relationship with the OT. The scenario was brought to an Adaptive Design workshop and after initial discussions, we started with rough prototypes to get the sizing right (Figures 1&2) and went from there.

2.2 FEEDBACK

In such situations it is sometimes difficult to get useful feedback on the emerging rough prototypes. People often need to be encouraged and supported to express their needs rather than simply acquiescing to the prescriptions of those who are perceived to be the expert. In my experience, designers are often tempted to 'take over' once they feel they have a grasp of the problem at hand (which is often way before the problem has fully been interrogated), and often clinicians act like they do in a hospital context and consult briefly and then move on to the next 'patient'. In our model we try to subvert these learned behaviors and defense mechanisms to encourage all participants to commit to the co-creation process**.**

Figures:1 & 2 Mum and Alley explore a series of rough prototypes co-creating with the clinician and designer (names changed).

An important aspect of this hands-on co-creative process is that conversations that might be otherwise awkward when conducted just in words become easier when facilitated by the use of 3D sketching and low-resolution prototyping. Mediated by objects which easily can be responded to, a different type of conversation begins - 'it's too high' - 'too wide'- 'not deep enough' - and sometimes even words aren't needed to elicit useful feedback that will help refine the design, especially when working with people who struggle to articulate their responses in words.

2.3 SWEAT EQUITY

We borrow aspects of the 'sweat equity' model pioneered by Habitat for Humanity (2023) to keep families engaged and encourage clinicians and designers to move beyond theory to 'get their hands dirty' in the making process. We have often found that this results in all parties feeling like they have learned new things that can be brought back into their lives 'beyond the triad', as they have stepped out of their comfort zones. Although many of the designers we work with have some 'making' experience it isn't always the case. We are continually reflecting on other roles in this creative mix. Stand-alone makers are a new category that is emerging and we are observing their particular impact in the co-creation relationship. One challenge with this role is that they can become detached from the co-creation process and focus solely on the making activity, which in turn allows less space for the families to input their sweat equity.

The 'sweat equity' element is purposefully encouraged at every stage of the process and results in a number of benefits. The first benefit is that the families feel a sense of achievement in the creation of the Adaptive Design. This in turn leads to an ownership of the design and the ability and motivation to care for and repair the item as it is used in their home. The designers and clinicians also benefit from the hands-on relationship with people who have different realities and challenges to them, and with the co-creative making process. Empathy is a necessary skill for both clinicians and designers and in our modern world it is all too easy to create our own bubble where such skills don't organically evolve as maybe they once did in day to day life. Finally, and perhaps most importantly, the mutual engagement builds trust and confidence in the design and guards against a blame culture or even a temptation to resort to litigation if over time the design fails to perform in the way it was originally designed. Fear of litigation has stopped similar programs over the years from making custom adaptations that have the potential of transforming the lives of all involved. Lawyers and other executives not involved in the co-creative relationship have misunderstood the shared ownership that is forged in the co-creation process, which results in care for its upkeep over its life-cycle, and an ongoing relationship rather than a transactional customer relationship. When asked about this, Truesdell stated, "We hold insurance but have never claimed on it for a failed device because we are all in this together as co-creators" (A. Truesdell, personal communication April 10th 2021).

In the illustration below we can see the three areas of the Triad illustrated as a Venn diagram. The shaded areas between the three circles indicate areas of shared and emerging knowledge that are generated through the growth of the co-creative relationship. As we all know, each of us are a complex intersection of expertise, experience and abilities. We may be an Occupational Therapist and also passionate about design, or a Designer passionate about the realities of the healthcare system and how it impacts people. The majority of us in Western Capitalist contexts have been brought up to understand that our job is our identity, hence one of our first questions when we meet people is 'what do you do?' Our education system places us in increasingly smaller boxes as our expertise gets deeper and narrower.

The late Sir Ken Robinson lamented that people don't "grow into creativity," but rather "we get educated out of it" by schools (Robinson, K 2005).

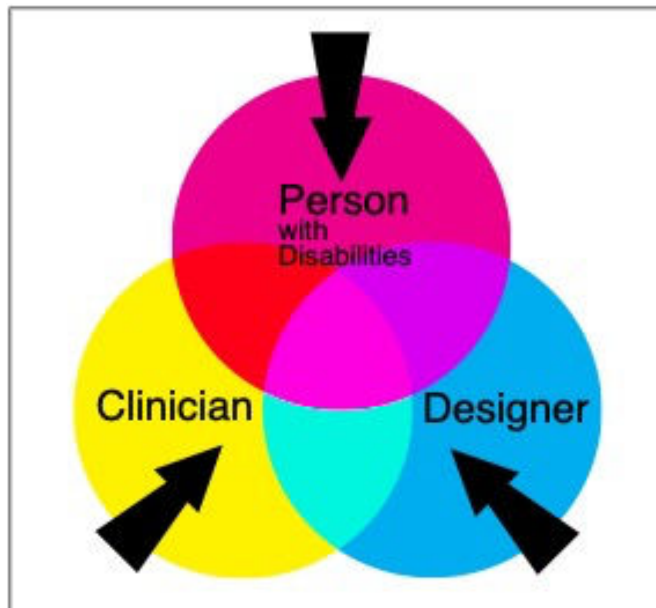

Figure. 3 the adaptive design triad [*Venn diagram of three colored circles labelled Person with Disabilities - Clinician and Designer with three corresponding arrows pointing towards the center].*

The triad allows for all participants to bring more of themselves to the creative process, more than simply their specific expertise to the joint undertaking. Clinicians that had to take choices early in their schooling away from design and making, get a chance to 'get their hands dirty' and solve problems in more iterative and practical ways. Designers in their turn, who took choices away from the natural sciences, get the opportunity to immerse themselves in the complexities of disability informed by the lived expertise of people with disabilities. Perhaps most importantly, people with disabilities who have gone through the school system being categorized as being 'in need' and not having agency or being seen to have the ability to be change makers in their own story, are placed at the heart of a creative relationship. As can be seen in the illustration above, the arrows indicate that to optimize the process, the 'experts' have to come together and develop trust in each other, finding shared knowledge and blending expertise, experience and abilities to arrive at a shared solution.

These practices have been refined by visionaries such as Alex Truesdell over the last 30 years (MacArthur Foundation 2023), and over the last seven years in our local teams. As a next step, we are beginning a broader longitudinal study, which will facilitate a closer analysis of the relationships and power dynamics at work, to tease out and refine strategies which will make this quiet revolutionary practice better understood and repeatable. As Pullin states "The design issues around disability are underexplored, and demand and deserve far more radical approaches*".* He goes on to say, *"*What is

needed is a truly multidisciplinary design thinking, combining and blurring design craft with engineering brilliance, therapeutic excellence, and the broadest experiences of the disabled people*"(Pullin, D 2009 p303).*

3. CONCLUSIONS

In conclusion, the question arises, what are we building here? The answer is more complex than a single customized Adaptive Design to meet the expressed needs of a single person with disabilities. It is broader, deeper and more significant than that. We are releasing human potential; we are building trust and relationships; we are building cooperation, capability and skills; we are building connections and communities of support; we are fostering hope that we can be the agents of the change in our own stories and we don't need to be solely reliant on what an insurance company approves. On a more existential level, we are building ladders and gates and battering rams to deal with the barriers and obstacles that many find in the way of more fulfilled lives. As Alex Truesdell stated when asked about Adaptive Design, "People think this is just a furniture workshop, but really we are an explosives factory"(Hendren, S. 2020 p71).

Figure:4 & 5. The final prototypes are tested. [Steps constructed from cardboard with handrails made from PVC tubing being used by child assisted by Occupational Therapist].

Figure 6. The final product is presented and Alley makes sure 'it's up to spec'. [Light blue steps constructed from carboard with handrails being used by a child with adults observing]. Figure 7. Nearly five years later, the well-used steps are returned because Alley has outgrown them [Brown steps constructed from carboard with hand rails].

When Alley had outgrown the steps they were donated back to the Adaptive Design workshop to be refurbished and modified for another family. I include this image to underline the durability and repairability of these materials that designers often don't use outside the model shop. As you can see, the color has been changed over the years to complement the décor of the space they were used. The family was a co-creation partner, and so they felt empowered to exercise their own design choices during the life of the item.

So what next? What will help get this innovation into the hands of the people that could benefit from it? We need to raise awareness of the benefits of Adaptive Design, for the more than one billion people (WHO, 2011), who are living with some form of disability, and at the same time help raise levels of basic skills in emerging clinicians and designers. We are already seeing the first 'green shoots' of this change in Central New York. Our loose collective is running training sessions and project-based learning with students in medicine and design. Arise Adaptive Design hosts volunteer designers, Occupational and Physical therapists as well as groups of Medical students. It is early days, but the aim is to prepare designers and clinicians with the knowledge and models of reflective approaches needed, and perhaps more importantly expose them to case studies of transformational change that will inform their practice and enable them to recognize where Adaptive Design might be able to help their future patients, users and ideally co-creation partners.

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