Disabled persons as lead users in product innovation: a literature overview

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Abstract
Lead users can be a valuable source for innovation. They are capable of detecting and experiencing needs before the general market does, and are willing to innovate because they can gain significant benefits if their needs are fulfilled. Several authors have highlighted the use of disabled persons, framed as lead users, to foster innovation in new product development. In this article, we review 18 cases where disabled users are framed as lead users, identifying common characteristics within these cases. The characteristics include the product categories where disabled lead user innovation occurs and how lead users were involved in these cases. Additionally, we look at the selection process of disabled lead users and how this relates to the classic approach of lead user innovation. Finally, we propose further opportunities for lead user innovation using disabled persons, and the challenges facing research in this domain.

Keywords: Lead users, product innovation, methods, disabled persons

1   Introduction

With reported high failure rates of new products [1], user involvement in product development is seen as a way to increase customer satisfaction, and is generally associated with positive effects such as increasing commercial success and strengthening customer understanding [2]. A wide variety of user involvement approaches exists, these include, but are not limited to, participatory action research, participatory design, open innovation, empathic design or user driven innovation [3]. Through methods such as generative studies, workshops and design games, designers can act as facilitator to translate wishes of participants into products or services but also through creating the appropriate environment so participants can express their needs [4], [5].

A very specific form of user participation is through lead users. According to von Hippel, (1) lead users are at the leading edge of an important market trend(s), and so are currently experiencing needs that will later be experienced by many users in that market, and (2) anticipate relatively high benefits from obtaining a solution to their needs, resulting in a high chance for innovation [6, p. 22]. Lead user innovation emphasizes a limited group of users, with specialized skills in specific contexts and with specific goals. Several cases highlight the

benefits of von Hippel's lead user method. These include the creation of banking services [7], product development at 3M [8], innovation in sporting equipment in general [9], and kayaks in particular [10], industrial equipment development [11] or medical device technology development [12].

However, lead users are typically rare [13]. The comparatively low amount of users have subsequent effects on the generalizability of concepts generated by lead users [14]–[17]. Their relative scarcity also means that it is easier to find lead users after innovation has already occurred, as opposed to before innovation has taken place [18].

Schuurman et al. [19], deconstructed the concept of lead users to identify 5 characteristics. These are, (1) high use experience, often gained through extreme use, (2) high product related knowledge, (3) new needs that have not been met by the current product or market, (4) dissatisfaction with the current offering to the point of not using a product anymore, and (5) users having innovated by themselves to create a new product.

This view aligns with alternative approaches of the lead user. These include general emphasis on extraordinary users, ranging between situational restrictions as a result of a user's environment [20], cultural contexts that lead to extraordinary use cases [21], and persons with disabilities [22]. The term disability in this context refers to situations where achieving certain goals are constricted. *A handicap results from the interaction between a disability and an environment; it does not flow naturally from the disability alone* [23]. Thus, when using the term, we refer to persons who can be described as having, what appears to be, an objective medical condition that is the cause of a disability.

Amongst the alternative views to lead users, persons with a disability are especially interesting candidates as lead users due to their adherence to two lead user attributes introduced earlier [24]: (1) experiencing a need that is not yet felt by the rest of the market, and (2) expecting high benefits from obtaining a solution. Arguably, these two factors have contributed to research about the role of disabled persons as lead users.

The examples span various domains, including mobile phones [24] or sports equipment [9], service design [25], assistive devices [26], or packaging design [27]. Within these cases, disabled lead users are sometimes selected from within a larger group of disabled persons [22], or framed as lead users through their disability [28]. These examples underline the potential of disabled persons as lead users.

However, within these cases (1) a wide variety of product domains exists, (2) the user selection procedure varies, and (3) how users are involved varies. The aim of this paper is to give a literature review on the selection process of disabled lead users within case study-based research and frame its relationship with the general approach of lead user innovation, while looking at the product focus, and user involvement.

2   Method

This literature review was conducted by searching journal papers, conference papers and books using the databases Google Scholar, Science Direct and Web of Science. We used a combination of the following keywords: "lead user", "disabled lead user", including more dated terms such as "handicapped users". References to von Hippel's lead user theory [29] were also searched for occurrences of such terms. These results were filtered to include cases

where the term lead user was associated with disabled persons. Papers were excluded when the term lead users were not specifically mentioned in relation to disabled persons.

We included results where the term lead user was used without specifically explaining the lead user method in detail. Examples are presented by case, as opposed to publication, since some articles contain more than one case. This review also excluded related examples such as persons who are temporarily incapacitated, including patients who just underwent surgery [30], or persons restricted artificially and framed as lead users [31]. However, as Engström and Snyder [30] argued, among patients there are also examples of so-called lead patients that offer valuable insights, but that is beyond the scope of this paper.

3 Review

We introduce our results based on three parameters. Firstly, we examine the product category within which disabled lead users can be found, distinguishing between assistive devices and more general mainstream products intended for broad audiences. Following this, we look at how lead users were selected, referring specifically to the user attributes - if any - that adhere to the lead user theory. Finally, we explore how lead users were involved during the process. Given space constraints, all cases are not introduced extensively for every attribute, but all cases are mentioned at least once throughout the review. However, an overview of all the cases and attributes can be found in Table 1.

Table 1: Cases overview

#	Product type	Lead User Selection	User Involvement	Case
1	Fruitball, an interactive game in the park	No specific mention of selection process	Various methods are mentioned, including brainstorms and evaluations of solutions.	[32]
2	Requirements for mobile phone use	No specific mention of selection process	Ethnographic methods such as photo diaries, open discussion, interviews	[24]
3	Packaging for a toothbrush	No selection, but the group also includes seniors and children, due to reduced motor skills	Collaborative workshops	[27]
4	Night-time telecare based support for people with dementia	No specific mention of selection process	Workshops, Interviews	[28]
5	Wetness alert sensors for urinary incontinent persons with dementia	No specific mention of selection process	Workshops, Interviews	[28]
6	Developing interfaces for people with brain injuries	No specific mention of selection process	Workshops, Interviews	[28]
7	Electric pot redesign various disabled persons	No specific mention of selection process	Workshop	[33]
8	Redesign of an umbrella, with a blind person or wheel chaired person in mind	No specific mention of selection process	Workshop format, compromising fieldwork, idea sketching, prototype construction and presentation	[33]
9	Signage for outside navigation	No specific mention of selection process	Workshop	[33]
10	Tactile maps that can be used by blind and seeing persons	Recruitment through organization for the blind, a selection was made, the process is not discussed	System evaluation, content creation and idea generation	[34]
11	Brain computer interface	Summarized as user disability, user interest and ethical process. Lead user was technically literate	Product evaluation, attending meeting with consortium members	[22]

12	Braking system for cyclists with one hand	Identification of innovation capability through questionnaire	Retrospective analysis of user-led innovation through questionnaires	[9]
13	Electronic ear technology to help people who are deaf identify critical sounds	Appropriate selection process is stressed, but the authors are not explicit about this.	Participatory development process for new product development, focus groups	[35]
14	Artificial limbs	No specific selection process, but barriers to participation existed and users had technical skills	Monthly meetings, formal event, discussing issues surrounding prosthetic limbs	[26]
15	YuType, add-on for keyboards to support typing	Most difficult case selected as lead user.	Online surveys, home visits, informal interview	[36]
16	Babelfish, sonic feedback concept for blind persons	No specific mention of selection process	Workshop setting during a 24h design challenge	[37]
17	User requirements for mobile phones for blind persons.	Recruitment through organizations for the blind, "savvy" users selected	One on one interviews	[38]
18	Service for blind persons	No specific review mentioned, but it is stressed that the lead user is active in the blind community	Introducing some concepts, idea generation and idea validation	[25]

3.1 Product types

When disabled persons participate as lead users, the product types are split in two categories. First, we identify the traditional approach [39], where some lead users are selected from within a larger group of disabled users. In this, selected users act as innovators for a product intended for use in a wider community of disabled persons only. Examples of this are the development of artificial limbs, as described by Rust and Wilson [26], or a service for blind persons that facilitates group learning [25], a brain computer interface [22], wetness alert for persons with dementia [28], or a concept device for blind persons to alert them about obstacles in public transport halls [37]. Due to their use domain, these examples are primarily focussed on assistive devices.

Secondly, involvement occurs in areas where disabled persons are not necessarily the only users of the intended product. In these examples, the products have a focus that is more general, with larger target markets in mind. For example, the design of a toothpaste package is the focus of Berg [27], while Shiose introduces a redesigned electric pot for persons in wheelchairs, blind persons and persons with cerebral palsy [33].

Specifically in the context of general use products in this category, we also identify the emphasis of inclusive design paradigms, where a disabled user is included in the design process to ensure that a broad spectrum of wishes are incorporated into the design such as was the case in [36], where a disabled lead user participated to create an interactive outdoor game that is intended for many park visitors.

3.2 User Selection

While the process of lead user identification is noted as an important step in the lead user method, there is a wide variety of ways how lead users are selected. They fall broadly within two categories.

The first follows the classic lead user method [39], where disabled lead users are found within a population of other disabled users. They display certain lead user characteristics such as willingness to innovate in order to solve a problem relevant to them [9], but also technical

proficiency, such as having a degree in computer science [22]. Thresholds to participation are also a mentioned method through which lead users might be filtered, as suggested by Rust and Wilson [26]. For others, being an active member of a local community of disabled persons suffices as lead user attribute [25]. Being the most difficult user to design for was mentioned by Gheerawo and Lee [36] as the rationale behind choosing a particular lead user, in their case a person with arthritis and neck stiffness. Because lead users are selected from within a group of disabled persons, with the goal of creating specific products for this group, the product focus within this approach is most often assistive devices or services.

This approach can be contrasted with cases where the disabled person was framed as a lead user as a result of their disability alone. To illustrate, Lee and Cassim [32] includes lead users in a wheelchair to develop a concept of interactive public gaming. This also applied with Hannukainen & Hölttä-Otto [24], where deaf and blind persons participated to identify customer needs for mobile phones. In this example, it was the specific intention of the authors to illustrate disabled persons' ability as lead users.

Finally, some authors do not specify any selection procedure at all, even though it might be plausible that a selection took place. For example, in Chamberlain and Dieng [34], a selection process is not stated, but the authors mention "two lead users" and a "wider forum with other blind members". However, in some cases in this review ([24], [28], [33]), no specific selection process is mentioned at all, but they arguably fall into the first category, where all disabled users can be seen as lead users as a result of their disability.

3.3 User Involvement

A final point of note is how users are involved. Within the cases examined the emphasis is on idea generation, but the elicitation methods vary and can be limited to telephone interviews [28], [38] or more involved participation, such as monthly meetings combined with a formal event [26]. To generate insights on the design of a device to notify deaf users of critical ambient sounds, Leahy [35] chose focus groups. We also find two examples where the lead user take on the role of researcher, performing duties such as testing the proposed product with other users and attending meetings with consortium members, as was the case with Lightbody et al. [22], or data analysis and idea validation [25]. Workshops are also prominent, where disabled persons are involved in ideation using a variety of methods that involve activities such as brainstorming or idea evaluation [32], [33].

While a majority of the cases cited are examples where researchers involve end-users in the design of new products or services, in Franke and Shah [9], disabled lead users were located after innovation took place. Here there is thus no user involvement in the sense that it occurs through a co-design process with a non-disabled designer, since the product (-adaptation) already exists, at least for the users who created their own solution.

4 Discussion

There are some limitations to the results. As mentioned earlier, cases where the term "lead users" was not used were not included in this review. It is arguable that more examples exist that follows the same basic approach. For example in Dong and Vanns [40] a new pill dispenser for people with MS was designed, where users are selectively involved - based on their particular symptoms - throughout the design process.

However, several themes emerge from this overview. Von Hippel initially framed the concept of lead users as arising from the premise that in high technology, or novel, product categories,

market research is not sufficient to discover latent needs [29]. In these categories, there are some very specific persons that are hard to find, who are experiencing a need that the market is yet to feel.

This principle has since been expanded and reframed to include a more expansive interpretation, as the cases presented in this review suggests. Hannukainen and Hölttä-Otto [24] argued that disabled users, because of exceptional experiences, can be seen as lead users. This is based on the premise that disabled persons adhere to two attributes originally set out by Von Hippel (needs and rewards). This relates to examples where the term lead user has been used more loosely and in direct relation to inclusive design approaches [33], [34], [36], [37], without mention of von Hippel specifically. In this, the selection procedure for lead users as used by von Hippel becomes less explicit, and lead users are viewed as such mostly through their disability. The lead user method thus acts as a way to achieve inclusive designs that appeal to large groups of users. This is a departure from von Hippel's original framing of product types falling into novel and high technology categories (such as industrial equipment development [11]), to include general use products and services (such as package design [27]). This approach arguably also draws on the notion that high contextual experience can be a source of radical innovation [41].

Nonetheless, we still identify the use of the lead user method in novel categories. These approaches resemble the classic lead user approach [39]. Disabled lead users are selected as part of a cohort of other disabled users, often due to higher technical skills or having adapted products to suit their particular needs. This does not differ vastly from how the lead user process is typically implemented, but the arguments why persons can be seen as lead users includes not only cases where the users themselves have come up with new innovations, but also being a lead user as a result of high involvement in a community, or barriers to participation.

5   Challenges and research outlook

As these case studies show, there is attention for disabled users as lead users for new product development, both for products intended for disabled persons and in examples where disabled persons act as a lead user for products intended for wider audiences. Below we introduce some challenges of this approach and potential avenues for further research.

5.1   Appropriate methods

To show the benefit of the lead user method, a common strategy has been to retrospectively analyse innovations. Lead users are thus located after innovation. However, if we take the view suggested by Hannukainen and Hölttä-Otto [24] that disabled users have a potential role to play in innovation, attention should be given to the methods used to involve them. This is especially important when using methods that go beyond interviews, such as co-creation methods or design games, notably in examples where products have not been created yet.

Compounding this problem, and also seen in this review, is that disabled persons also do not constitute one homogenous group and even within a particular disability, nuances exist. This further emphasizes that it remains important for tools to be focussed on the person or disability type. While approaches such as design games [4] are good sources for generative research with non-disabled persons, their methods cannot always be applied in a setting where participants have a disability.

To illustrate, co-creation with deaf persons might require translators, while blind persons have no possibility to read written notes or summaries, making synthesis of ideas harder. Furthermore, blind persons would either need braille printed informed consent forms, or need an objective person present to read and sign the appropriate forms.

Involving disabled persons in co-design efforts also raises some ethics consideration. For instance, managing expectations is important. To illustrate, Frauenberger et al. specifically mention issues encountered when co-designing with special needs children [42]. The use of proxy users in these cases might also be of value. While it is not recommended in all cases, in certain contexts where participants are unable to communicate, a proxy user might be used. Examples would include persons with Alzheimer, or dementia [43]. Note that the surrogate, in the form of a family member or caregiver might also be a lead user, through high needs, and expected high benefits when a solution is found.

5.2 Exploring alternatives

As mentioned, the literature shows that the attention for disabled persons as lead users is broadly contained in two product categories: products intended for a cohort of disabled users, mostly assistive devices, and products for wider use, intended for mass markets (see Figure 1). However, following Kristensson and Magnusson [41], high use experience can be a driver for innovative idea generation. Pullin and Newell [44] also suggest that users with extraordinary experience might be good sources of innovation. As noted by Cassim and Dong, people faced with disabilities employ various coping strategies and *offer radical alternatives to standard consumer behaviour* [45].
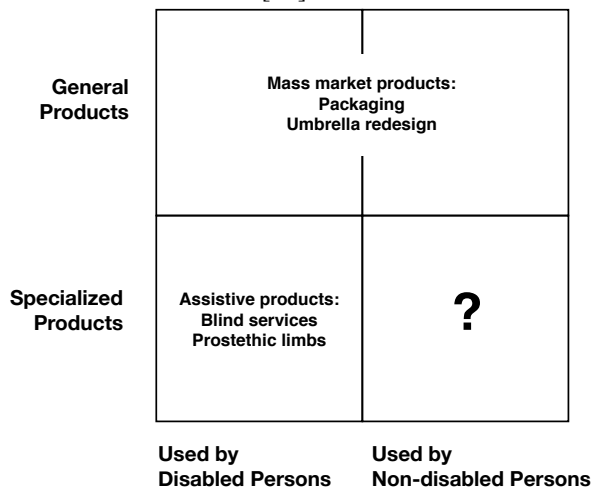

Figure 1: Product categories for disabled persons as lead users in product innovation

However, we currently identify a lack of examples where disabled persons are involved as lead users for products that they might not necessarily use. This principle is not without precedent. For example, extreme experience in one domain has been shown to be able to trickle down to related products. The developed product might not necessarily benefit the lead users themselves. Examples are Old Order Mennonites, a group that, due to their low resource consumption, offered valuable insights to encourage environmentally conscious behaviour [21]; Orthodox Jews' home automation innovations [46]; or veterinary surgeons as inspiration for health and safety innovation, due to extreme context of their work (dirty patients, no health insurance) [39].

Given these examples, we argue that disabled persons' experiences can have valuable insights for certain use contexts. These may include contexts where persons with no problems with sight, hearing, or movement, may need to operate in extreme environments. Additionally, disabled persons may offer new ways of interpreting and using existing products and technology, having re-appropriated products to suit their specific needs, thus offering novel ways of product use that might not occur to non-disabled persons, as suggested by Cassim and Dong [45].

6 Conclusion

This paper introduced a review of 18 cases where disabled persons, framed as lead users, played a role in product innovation. Cases were introduced based on product types, lead user selection and user involvement. The cases argue for the benefit of using persons with disabilities in the design process. This includes products that the disabled users might use themselves or those intended for a general audience, such as general use products. For future work, we argue that an emphasis is needed on appropriate methods of disabled lead user involvement. Additionally, research is needed into the role of disabled persons as lead users for products in domains where they are experience experts, but not necessarily end users.

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