Empowered participation of users with disabilities in R&D projects

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This paper provides an introduction to empowered participation of users with disabilities in research and development (R&D). It is based on the experiences of the European project FORTUNE (Bühler, 2000). Introductory experiences about the state of the art of disabled user involvement in European R & D are reported. The value of participation of users with disabilities is discussed. An overview of the FORTUNE curriculum and training is provided. The FORTUNE concept of user participation in projects is introduced as a reference model for participation of users with disabilities, followed by a scheme of criteria for the assessment of user participation as a practical tool. A brief overview of methodologies for user participation and potential organizational frameworks is presented.

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1. Experiences of user involvement in European R&D

A validation inventory of European R&D programmes underpinned the benefit of user participation for R&D. However, the investigation of validation practice in the European 3rd Framework Programme showed that the knowledge and practice of structured user involvement in R&D is generally low. The evaluation board and committee of the TIDE (Technology Initiative for Disabled and Elderly) pilot phase realized that "the most successful projects had the enthusiastic and active involvement of established, formal user organisations" (European Commission, 1994*a*).

Very good field work is performed by democratic self-help organizations on a voluntary basis. Mostly users have joined these organizations due to their particular impairment or disability. However, barriers to participation in R&D programmes and projects are experienced by many groups, and the contact between developers and end-user organizations is generally weak. Likewise, the knowledge of end-users about the new opportunities provided by technological solutions is low. Many organizations have a voluntary work basis and an internal structure, which is not yet prepared for procedures in European R&D work. Furthermore, not enough well-trained users from user organizations are available to act in the R&D context in a professional way.

The R&D community is in principle prepared to interact with users. However, user participation is still often reduced to being a subject of study, or to be involved late in the project lifecycle in connection with prototype testing. There is a need to change attitudes and approaches toward user participation (Treffers, 1998; Long and Hunt, 1999). In order to reach the broadest user group and a variety of situations, people with disabilities must be included in the R&D process. Many players in industry and research and development have no experience in this respect.

The EU Telematics Applications Programme has focused on the importance of user oriented R&D. In the "Ten Commandments" of the Programme for the period 1994–1998 (European Commission, 1994*b*) it is stated that the projects shall "Be user-oriented and cost-effective rather than technology-driven", and to "Associate users' representatives at each stage of a project". The importance of user input for success in the market is also emphasized in the USA (Leahy, 1999). This analysis and situation stimulated the FORTUNE project to start making skilled resources available to R&D projects. Experience and guidance based on the FORTUNE project (Bühler, 2000) may help to improve this situation.

2. The platform for user participation

Traditionally, user needs and user constraints have been assessed by market research. However, it has become evident that good market data alone will not guarantee any success, unless user demands can be met (Leahy, 1999). Hence, users have quite often been involved in a programme or a project. Mostly, the involvement is carried out rather late in the lifecycle of the activity. Typically, users are being invited to take part in a review process, when the most important work has already been carried out. Mostly the possibilities to influence and change things are not overwhelming but very limited. In R&D related work, users traditionally may enter the scene during the final testing of products. Moreover, in some instances in the past it may be fair to state that user participation has rather been more on paper, than real participation and influence. Often users may have been invited to take part in for instance reference groups, and been expected to take part without any payment. Quite rarely, users have taken part in the initial stages of projects, in the idea conceptualization, or as full partners in a project team. The situation as described above constitutes a challenge both to the R&D world and to the user organizations.

On the other hand, users claim that the effectiveness and outcomes of research can be improved by users' participation. It is noted that users need to accept new products and services to open up real markets, that only user satisfaction will lead to continuous market success, that users know best what their needs are, that users can detect what works in practice, and that users may abandon products and services for reasons other than the functionality of a product. In consequence, the USA rehabilitation engineering research centre on technology evaluation and transfer has promoted concepts for user involvement already in the idea generation, concept definition, concept screening and prototype evaluation (Jain & Usiak, 1997). Thus, users are considered both as a market force and as a valuable source of input during the R&D phase: not only for asking users' opinions when testing prototypes, but rather to consider users as partners in R&D.