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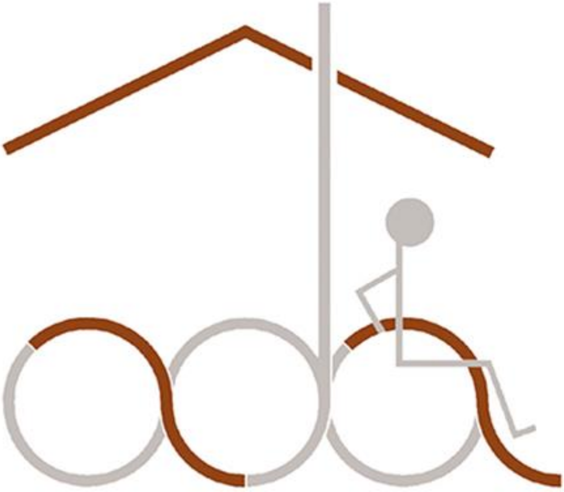
Designing Autonomy at Home. The ADA Project

An Interdisciplinary Strategy for Adaptation of the Homes of Disabled Persons



STUDI E SAGGI

– 199 –

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Foreword

Stefania Saccardi[1]

For many years, Tuscany Regional Government has been involved in the promotion of policies that define a central role for the disabled person developing their capacities and potential for growth in directions that are not those of pure welfarism. These policies aim to develop autonomy and personalise interventions. Indeed, only through greater levels of autonomy will the disabled person be able to participate in the social life of the community, have access to employment, and prepare themselves for the "after us" phase, namely when they will no longer be able to rely on the support of parents as main caregivers.

From our perspective, accessibility at all levels, from private and public environment to education, employment, information, and services, as well as transport, cultural and recreational services, becomes a prerequisite for allowing the disabled person to enjoy all human rights and fundamental freedoms: it must be guaranteed in all spheres of a person's life.

Actions put in place by Regional Government to promote independent living, remove architectural barriers, simplify access, etc., make Tuscany one of the most advanced regions in Italy, including from the perspective of overall financial commitment.

Tuscany Regional Government supports actions to offer frail and disabled persons an autonomous way of life and social integration, identifying the most adequate and efficient solutions to increase levels of accessibility and usability of the territory.

The ADA Project described in this book represents another step forward on the path toward providing care for the disabled person, with the purpose of making the home environment more autonomous, accessible and practical.

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[1] Tuscany Regional Government Councilor for *Health, Welfare and Social-Health Integration and Sport.*

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These are certainly long, complex projects, to be developed in tandem and requiring a high level of participation by the disabled persons themselves, their families, and the associations representing them, as well as the institutional and voluntary sector agencies engaged in different roles and with different responsibilities, but all sharing the aim of guaranteeing the best possible quality of life.

Preface

Antonio Laurìa

This book describes the ADA Project, an action research developed by the University of Florence (Department of Architecture – Florence Accessibility Lab Interdepartmental Research Unit) and commissioned by Tuscany Regional Government.

The ADA Project was already described in a previous book published for Italian readers (Laurìa *et al.*, 2017) but this new edition includes the latest research developments and previously unpublished features. Moreover, contents have been organised to appeal to the international reader. New parts were written, others modified, and the bibliography, tables and images were improved and honed. Parts which would not have been meaningful to non-Italian readers have been deleted; other parts were added with the purpose of elucidating for foreign readers certain issues peculiar to the Italian context. The methodological design of the research and its operating tools have been fine-tuned and are described in their definitive version, excluding all the intermediate passages illustrated in detail in the Italian original.

Accessibility of the book was also taken into account, to render the contents truly straightforward for the widest possible spectrum of users, including those who are unable to see images and complex tables. Specifically, alternative descriptions are provided for any non-textual section, to provide the sight-challenged reader with equivalent content.

The book is divided into two sections: the first outlines the theoretical framework of the ADA Project and the cultural principles upon which it is based; the second describes planning stages and operating tools in detail.

Section one examines the personal and environmental factors (both physical and socio-cultural) that characterise life at home for disabled persons and their caregivers. The evolution of the concepts of disability, personal autonomy and independent life are discussed. The issue of adapting the domestic environment is then analysed through the description of sev-

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eral methods and tools, and the subject of *housing adaptation* is introduced through the description of intervention strategies and criteria.

Section two is the core of the book: it provides a methodical illustration of the various phases of the ADA Project, its aims, its recipients and beneficiaries, as well as the procedure and tools used, the players and the relationships with the agencies involved. In particular, a tool for data production and needs assessment (the ADA Assessment Model – AdAM) is carefully described. This tool represents the main scientific and methodological outcome of the ADA Project and is reproduced in full in the Annexe to the book.

Since most challenges addressed by the ADA Project are general in nature and might be met in any context, I hope the reader finds food for thought in the research described in this book, as well as some interesting ideas useful for their own work.

In 2018 the ADA Project was first selected as “Good Practice” by the international Design for All Foundation and then won the “Design for All Foundation Award 2018,” in the category “Spaces, products and services already in use.”

Credits

The ADA Project's methodological design and operating tools were conceived and gradually perfected (also in collaboration with other partners)[1] by the research group put together at the *Florence Accessibility Lab* Interdepartmental Research Unit of the University of Florence, which comprised Antonio Laurìa (AL), Beatrice Benesperi (BB), Paolo Costa (PC) and Fabio Valli (FV).

The book is the result of the collective work of its four authors and their various roles are detailed below.

Antonio Laurìa coordinated the scientific project for both the research and the book; he wrote the Presentation and the Conclusions of the book, as well as paragraphs 1.1, 1.2, 2.1, 2.2, and 2.3. He also wrote, with BB, PC and FV, Chapters 4 and 5, and the Annexe.

Beatrice Benesperi wrote paragraphs 1.3, 1.4, 1.5, 2.4, and edited the bibliography. She also wrote, with AL, PC and FV, Chapters 4 and 5 and the Annexe. Finally, with PC, she wrote image captions for the visually impaired.

Paolo Costa wrote, with AL, BB, and FV, Chapters 4 and 5, and the Annexe. He supervised the edition and the English translation of the manuscript. With BB he wrote image captions for the visually impaired.

Fabio Valli wrote Chapter 3, and with AL, BB and PC, Chapters 4 and 5, and the Annexe. He also edited the tables and images included in the book.

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[1] The ADA Project was carried out by personnel from three different agencies: (1) Tuscany Regional Government (through the *Health, Welfare and Social-Health Integration and Sport* Department, the *Regional Accessibility Centre*, the *Health Districts* and *the Learning and Communication Aids Labs*), (2) the University of Florence (through the Department of Architecture – *Florence Accessibility Lab* Interdepartmental Research Unit), and (3) The National Research Council of Pisa (through the "A. Faedo" Institute of Science and Technology of Information – *Signals and Images Lab* and *Human Interfaces in Information Systems Lab*).

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Additional contributions

Angela Arnone edited and revised the English text.
Junik Balisha wrote paragraph 2.5 and prepared all the figures and tables included in the book.
I.RI.FO.R. Toscana assisted with the edition.
Luis Gatt translated the manuscript into English.
Barbara Leporini supervised the alternative textual descriptions of the images for visually impaired people.

Acknowledgements

The ADA Project began in April 2015 and is currently in progress. During this relatively long period, a series of wonderful relationships were established among the people who took part in the project and we wish to express our gratitude to them.

First of all, we would like to thank all the disabled persons who participated in the ADA Project, as well as their families. By welcoming us into their homes with trust and curiosity, speaking to us about their experiences, their desires and their life projects, they made the project more meaningful and enhanced our skills and awareness.

The close and productive cooperation between the Health, Welfare and Social-Health Integration and Sport Department of the Tuscany Regional Government and the Florence Accessibility Lab Interdepartmental Research Unit of the University of Florence was one of the reasons for the success of the ADA Project. In this respect we wish to thank Councillor Stefania Saccardi who believed in the ADA Project and supported it wholeheartedly.

We also wish to thank Barbara Trambusti, head of the General Office for Citizen Rights and Social Cohesion – Social and Healthcare Integration Policies Sector of Tuscany Regional Government, who always encouraged us and generously offered us her time and attention. We also thank two members of her staff, Giuseppina Attardo and Davide Ricotta, for their support to the Project.

Our gratitude to Franco Doni and Laura Zecchi – respectively Director and Programming Coordinator of the "Fiorentina Nord Ovest" Health District – for their commitment and cooperation while performing the delicate task of providing administrative coordination for the ADA Project on behalf of the Tuscany Regional Government.

If the ADA Project was carried out as planned, overcoming every obstacle and difficulty, it is due largely to the enthusiasm and generous and com-

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petent commitment of Andrea Valdrè, coordinator of Tuscany's Regional Accessibility Centre. We wish to express our personal thanks to him and to his team – Adriana Ferrara, Chiara Bondielli, David Burgalassi and Roberto Sarti – for the dedication with which they addressed and resolved a series of problems, both small and large.

It is also our duty to thank all those who worked with us in the fulfilment of the ADA Project. It would be impossible to mention everyone but we are particularly grateful to all the physicians and social workers who were part of the work groups, and all the administrative personnel of Tuscany's health districts.

For the quality and continuity of their contribution, a special mention goes also to Annaugusta Alimenti, Giuseppe Fusco, Barbara Leporini, Cecilia Lombardi, Alessandro Lussu, Anna Chiara Marini and Laura Rosiello and the research fellows of the University of Florence's Architecture Department: Chiara Angioli, Enrico Cibei, Lucas Frediani, Giordana Gregori, Marco Mariotti, Nadia Recca, and Lulghennet Teklè.

Barbara Leporini and Antonio Quatraro deserve special thanks for their precious supervision of the version of the book for the visually impaired.

Our sincere thanks go to Marta and Massimo Tilli for their generosity in revising the ADA Assessment Model from a medical perspective, and to Sergio Aito and Adam Wood for their precious advice.

We wish once again to thank Junik Balisha, PhD student in Architecture at the University of Florence, who did such an excellent job preparing and presenting the tables, figures and images included in the book and wrote paragraph § 2.5, Luis Gatt, of the University of Florence's Architecture Department Image and Communication Lab, who translated the manuscript into English, and Angela Arnone who edited and revised the English text offering valuable advice and suggestions.

Finally, we wish to express our appreciation to the administrative personnel of the University of Florence's Architecture Department, and in particular to Gioi Gonnella, Donatella Cingottini, Stefano Cocci, and Anna De Marco for the professionalism and care with which they carried out the complex bureaucratic procedures concerning the ADA Project.

Antonio Laurìa, Beatrice Benesperi, Paolo Costa and Fabio Valli
Florence, January 2019

Introduction

The ADA Project (*Adattamento Domestico per l'Autonomia personale* – Adaptation of Homes for Personal Autonomy) is a Tuscany Regional Government *action research* dedicated to persons with severe disabilities and their caregivers in their home environment. It intends to increase domestic autonomy by adapting home space, furnishings, equipment and technological installations.[1]

It comprises three *implementation phases*: (1) the *site survey* undertaken at the dwelling of the disabled person, to bring to light their needs and wishes, (2) the *accessibility recommendations* suggesting an intervention framework for adaptation of the homes of the disabled and their families, and (3) *case assessment* to define and assign regional grants for entitled disabled persons.

The methodological design of the ADA Project envisages a *preparatory phase* before the implementation phases, and an *ex-post evaluation* phase downstream of the implementation phases.

The preparatory phase intends to draft procedures and operating tools, and train those who perform data collection and administration procedures during the implementation phases. The ex-post evaluation phase intends to assess the efficiency of the process and the relevance of its results[2].

The ADA Project was composed of two different stages: the first, aimed primarily to field-test procedures and operating tools, regarded only two of

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[1] The methodological design and operating tools of the ADA Project were developed by a research group of the Florence Accessibility Lab Interdepartmental Research Unit (FAL) of the University of Florence, comprising Antonio Laurìa (principal investigator), Beatrice Benesperi, Paolo Costa, Fabio Valli (researchers), and Junik Balisha (associate researcher).

[2] The ex-post evaluation phase is still in progress and will then be the subject of a future publication.

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Tuscany's health districts[3] (pilot stage);[4] the second stage went on to extend the ADA Project to the entire region.[5] Both the procedures and operating tools used during the first stage underwent a careful step-by-step revision based on results and empirical knowledge progressively acquired during fieldwork.

The ADA Project can be shown succinctly as a four-dimensional matrix, as seen in Fig. 1.

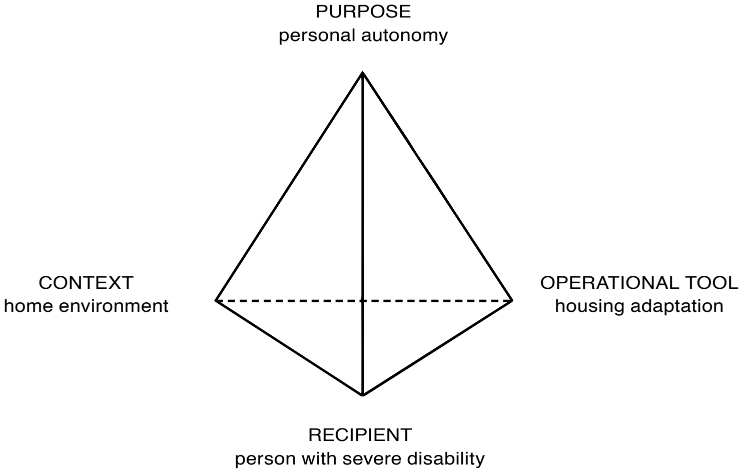

Figure 1 – The ADA Project as a four-dimensional matrix on how to achieve personal autonomy for severely disabled persons in their homes.

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[3] In Tuscany, healthcare and social services are implemented at local level by health districts (*Zone Distretto*) coordinated by Tuscany Regional Government. Recently territorial distribution of health districts was reorganised: the thirty-four health districts that started the ADA Project in 2015 where rearranged to become twenty-six in 2018. Some of the health districts are organized as corresponding *Società della Salute* (literally, *Health Companies*) which are non-profit public agencies that integrate the healthcare and social services of the health district with those offered by the municipal authorities located in the same health district. For the sake of simplicity, we always use the label "health district", without specifying if ADA Project activities were actually organized with the health district or *Società della Salute* personnel.

[4] After some months of preparation, the ADA Project pilot stage officially began on 22 April 2015, through a call for applications made by the two adjoining health districts (Fiorentina Nord Ovest and Pratese), known as "Housing adaptation: consultation and grants for persons with severe disabilities for 2015" ("Adattamento domestico: consulenze e contributi per persone con disabilità grave – Annualità 2015"). There were thirty-six participants in the pilot phase.

[5] The extension of the ADA Project to the entire region took place through a call for applications published by Tuscany's thirty-four health districts in November 2016. There were 326 participants. The upscaling required in-depth revision of procedures and operating tools.

The purpose of the ADA Project is to increase *personal autonomy* of the severely disabled person in their home environment. Autonomy is a multidimensional process which tends toward self-determination of the person. Since being human includes the concept of autonomy, the addition of the adjective "personal" may seem pleonastic but here the term is used to underscore that improving autonomy should be a highly personalised process and one that respects the pace and methods desired by the disabled person (see Ratzka, 1989).

The beneficiary of the ADA Project is the *person with severe disability*. In Italy, the condition of severe disability is defined by the existing regulatory framework based on the extent to which a person's autonomy is limited in performance terms.[6] Regulations, in other words, focus on the *effects* that the functional limitations (motor, sensory perception, mental, behavioural, etc.) can generate in a person's everyday life. Statistical data to illustrate the numerical framework of disability (see ISTAT, 2014) assume as a reference personal capacity in the undertaking of certain activities of daily living (ADLs – *Activities of Daily Living*) (Solipaca, 2009).

The *home environment* is the heart of the ADA Project. It relates to a deep-rooted sense of identity, intimacy and protection; it is the place of family memories; it is the primary space "containing" our bodies, our stories, our needs and desires; it is the interactive context that affects many of our activities (Norberg-Schulz, 1985). For the disabled, home often represents the context where most everyday activities are undertaken. In particularly serious cases, or when family links and social opportunities are weak or broken, home is the extension of their range of activity in the world, the entire horizon of their existence. Since it has such a delicate and significant role in the life of the severely disabled person, the home environment represents a particularly important subject for reflection in terms of public policies intended to support their rights as citizens. The home environment is also the ADA Project's area of operation, so everyday activities outside the home environment (for example, going shopping), while extremely significant, do not fall within the scope of the research. In this respect, the ADA Project must be integrated with other measures whose aim is to improve the degree of accessibility of urban spaces, transport, and public buildings, or those intended for public use (see Laurìa, 2012a; 2014a).

Housing adaptation is the main support offered by the ADA Project for the severely disabled (and their caregivers) for undertaking of domestic activities. It is a dynamic, two-directional process (see French *et al.*, 1982; Edwards *et al.*, 1998), comprising on the one hand the conversion of the environment (physical and social) to suit human capabilities; on the other, the resilience of the individual towards the demands of their environment

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[6] See Art. 3, para. 3 of Law 104/1992, as subsequently amended and supplemented.

(see Kreisler, 1996; Carver, 1998). This process is regulated by *human needs*, the meeting point – as Heschel (1951) writes – between the interior world and the environment. In the case of frail and disabled persons, the process of environmental adaptation is heavily "unbalanced" since their prospects for responding efficiently to the demands of the environment are reduced or compromised by their functional limitations. In particular, for persons with severe disabilities, even slight disparities between what is necessary or desired and what is concretely possible, can compromise or obstruct the process of environmental fit. Consequently, the ADA Project – together with the biopsychosocial model of disability,[7] advocated both by the World Health Organization through the *International Classification of Functioning, Disability and Health* (ICF) (WHO, 2001; Barnes & Mercer, 2005; WHO & WB, 2011), and by the United Nations through the *Convention on the Rights of Persons with Disabilities* (CRPD) (UN, 2006),[8] and with the *human-centred* approach to design – focuses on the changes to the physical environment *in favour* of the disabled person, and in particular on the enhancement of the *degree of accessibility*[9] of the home environment. This goal is strengthened by collateral actions, such as rehabilitation interventions and welfare support, aimed at exploiting personal motivations and aspirations, as well as personal capacities and social relationships.

This book describes the cultural background and the main sources of inspiration of the ADA Project (Chapters 1 and 2), and its phases and its means of implementation (Chapters 3, 4 and 5). The phases and means are illustrated taking into account all the progress that was made during the research from the very start.

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[7] See § 1.2.

[8] According to the *Convention on the Rights of Persons with Disabilities,* anti-discrimination protection is based on the obligation to adopt *reasonable accommodation* (see Cera, 2010). This rather ambiguous obligation (how do we define "reasonable") is related to the questionable wish to balance fulfilment of the rights of the disabled with the economic resources available (always lacking, by definition) (Deidda, 2014). Translated into environmental terms, this means that it is not always possible to adapt everything "reasonably".

[9] The "degree of accessibility" is a subjective and dynamic assessment of the conditions of accessibility of a certain place, item or service, which depends on the characteristics of the person in question, the physical environment and the socio-cultural context. The possibility of increasing the degree of accessibility of a place depends on some of its inherent features, such as its reachability and tolerance to change (for example historical, architectural and structural restrictions), as well as on external factors such as the quality of the adaptation/refurbishment project, the quality of the participatory process, the regulatory framework, the availability of financial resources, the quality of the implementation and management, etc. (Laurìa, 2012a; 2014a; 2016b). Cf. Danford & Steinfeld, 1999; Steinfeld & Danford, 2000; Sakkas & Pérez, 2006). For attempts to measure the degree of accessibility issues in the home, see the *Housing Enabler* (Iwarsson & Slaug, 2001).

SECTION I

Theoretical framework

CHAPTER 1

Basic concepts

The promotion of personal autonomy is one of the fundamental values of policies in favour of disabled persons. Personal autonomy is generally interpreted as the ability to carry out certain activities without the assistance of others or, in a wider sense, as the capability to design one's own life project, relate to others and, with others, cooperate in the development of society. This second interpretation is strictly linked to the principle of self-determination of the disabled person and of their involvement in the life of the community (independent living).
In this chapter, after a reflection on the concepts of normality and disability, and on the process of environmental adaptation, we outline the more recent evolution of the meaning of disability and discuss the concepts of personal autonomy and independent living.

1.1 Normality/Disability

Giuseppe Pontiggia, in his book *Born Twice*, addresses the issue of the relationship between disability and normality perfectly, explaining how "it's not by denying the existence of difference that we can fight it, but by modifying our image of the norm." Pontiggia does not ignore the existence of differences but places them in a broader perspective "accepting and transcending them." He thus highlights the theoretical weakness "both for those who make differentiation into discrimination and for those who try to avoid discrimination by entirely denying the existence of difference" (Pontiggia, 2002: 28-29).

Pontiggia's theoretical view seems fundamental for a correct definition of the complex questions regarding the social integration of disabled persons and the full exercise of their citizenship rights. At the same time, this seems very difficult to put into practice.

To allow disabled persons to enjoy the same rights as others would, indeed, require a shift in the paradigm our society applies with regard to the actual meaning of "disability", as well as overcoming or de-structuring disability as a social category.[1] First of all we would need a perspective of social cooperation no longer based on reciprocal economic benefit, but rather on benevolence and altruism (Nussbaum, 2011). It would then be necessary for disability policies to stop being *special* and simply be *ordinary.* In other

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[1] See also § 1.3.

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words, implementing a *mainstreaming strategy*, the subject of disability would no longer be an afterthought – based on adjustments and compromises – to general decisions made, but an organic part of these decisions (see Commission of the European Communities, 2003).[2] On the other hand, evidence of weakness in the boundary between ability and disability,[3] the rising incidence of disabled persons as an epiphenomenon of the betterment of living standards, diagnostic and therapeutic progress in the medical field, and the consequent evidence that, in a certain sense, the entire population is "at risk," in terms of chronic disease and disability, seem to validate the need to overcome *special* policies and rely on *universal* policies instead (Zola, 1989).[4] This need exists at all levels: from the creation of laws and institutions at the core of society to regulations concerning employment, education, health, construction, and so on.

The architectural design process would be an apt metaphor for the widespread manner of understanding disability. Usually, the topic of accessibility (or more typically, that of the elimination of architectural barriers) does not inform the early stages of design and is addressed by architects and designers as a simple regulatory requirement after the main design decisions have been made and the *system of constraints* (aesthetic, technological, structural, plant engineering, functional, etc.) has been defined. The result is that the solutions provided for satisfying the needs of the disabled do not appear as an integral, coherent part of planning overall but as *prostheses,* namely artificial and often functionally and semantically questionable grafting of alien parts onto a "body" that continues to be similar to itself (Laurìa, 2012c).

Modification of the image of what is the norm that Pontiggia describes, questions each of us on how we address the subject of disability (and other social diversities), our intention to make a sincere commitment to adapting our values and behaviour to understand others and welcome them into our shared living environment.

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[2] Mainstreaming as a concept refers to a process that turns into a system and generalises experiences, innovations and specific requirements. "The mainstreaming strategy implies the integration of the disability perspective into every stage of policy processes – from design and implementation to monitoring and evaluation – with a view to promoting equal opportunities for people with disabilities." (Commission of the European Communities, 2003: 13).

[3] Observing the brain's extraordinary capacity to adapt, the famous neuro-psychiatrist Oliver Sacks asked himself "whether it may not be necessary to redefine the very concepts of 'health' and 'disease', to see these in terms of the ability of the organism to create a new organisation and order, one that fits its special, altered disposition and needs, rather than in the terms of a rigidly defined 'norm'." (Sacks, 1995: XVII).

[4] Zola (1989: 406) wrote that: "Only when we acknowledge the near universality of disability and that all its dimensions (including the biomedical) are part of the social process by which the meanings of disability are negotiated will it be possible to appreciate fully how general public policy can affect this issue."

1.2 Person-Environment Fit

The *living environment* is not a neutral space, but always an "operating factor" (Fitch, 1972; Canter & Lee, 1974) of human life. The environment dynamically shapes the behaviour, expectations and aspirations of those who inhabit it. In turn, the inhabitants intervene constantly in its transformation (see, *inter alia*, Lawton & Simon, 1968; Boudon, 1969; Alexander, 1970; Lawton & Nahemow, 1973, Lamure, 1976; Lawton, 1982; Steinfeld & Danford, 1999; Scheidt & Norris-Baker, 2004; Laurìa, 2017b) in the attempt to adapt it to their changing needs.

> A well-known theoretical instrument to analyse the person-environment relationships is the Lawton and Nahemow's (1973) *ecological model* and the accompanying *environmental docility hypothesis* (Lawton and Simon, 1968) (both developed in gerontology) focused on the interaction between "individual competence" and "environmental press". Their essence is that as competence declines, the person is less able to address environmental press. Competence is defined as the aggregate of the person's abilities; environmental press is interpreted in positive or negative terms based on reciprocal action or influence with the person. Competence, like environmental press, can change over time.

The environment not only defines to what extent an impairment is *disabling* (see, *inter alia*, WHO, 2001, all. 4; Gray, Gould & Bickenbach, 2003; Oliver, 2004; Traustadóttir, 2009), but also the degree to which a certain solution for increasing accessibility is *enabling* (Laurìa, 2014a). For this reason, the assessment of each disabled person's profile must combine traditional medical diagnosis with the features of the physical and social environment in which the person in question lives (see Mace, Hardie & Placie, 1991).[5]

> Sacks (1995: XX) mentions that the great french neurologist François Lhermitte "instead of just observing his patients in the clinic, makes a point of visiting them at home, taking them to restaurants or theatres, or for rides in his car, sharing their lives as much as possible."

In the process of *disabled person-environment fit*, the configuration (in terms of morphology and dimension) of spaces – as already mentioned – plays a very important role.[6] Comparing similar functional and other existential and social condition limitations, the more accessible the living environment, the greater the capacity of the person to self-determine their

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[5] See § 2.2.

[6] Inaccessibility of environments is one of the most extensive discriminations suffered by disabled persons. In 1982, a report by the UK's *Committee on Restrictions against Disabled People* (CORAD) highlighted how for many disabled persons, the difficulty of access represented "the fundamental cause and manifestation of discrimination." (CORAD, 1982: 9). Cf. Barnes (1991: 173).

own existence. This suggests that introducing modifications to the living environment that can grow the *degree of accessibility*, will lead to positive effects on the well-being of the person, on their capacity to develop their own *life project* and to participate in a direct and personal manner in collective life and the development of society. When a living environment is not adequate, it not only prevents or impedes performance of activities, but also conditions the conformation of the true "I" of the human being, the constitution of their personality.[7] For example, a young disabled man chooses a course not based on his capacities and aspirations, but on the degree of accessibility to places and services, his freedom and life project are irreparably compromised.

The *living environment* is strongly influenced by the social structure in which a person lives their existence (family, community and society). Brandt & Pope (1997) described the environment as an entity in support of the person, as a sort of three-dimensional mat with social factors on one side and physical factors on the other. The capacity of the environment to support people's lives adequately (expressed in the metaphor by the flexibility of the mat) depends on the one hand on its physical accessibility and on the other on the efficiency of the social support network available (Fig. 2).

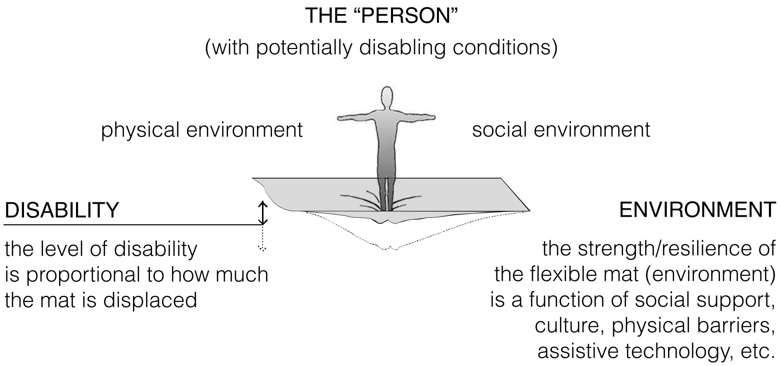

Figure 2 – Disability as displacement of the "environmental mat." The amount of displacement represents the amount of disability experienced by the individual; it is a function of the strength of the physical and social environments that support an individual and the magnitude of the potentially disabling condition. [Adapted from Brandt & Pope, 1997]

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[7] Ortega y Gasset's well-known phrase "Yo soy yo y mi circunstancia" (Ortega y Gasset, 1914), underscores reciprocal influences, the entangled mesh of relationships between the person and their living environment. As Ortega y Gasset says, the human personality is not an independent reality but exists only in relationship to the surrounding world and the objects and relationships constituting it.

1.3 On the Recent Evolution of the Concept of Disability

In the 1970s, thanks to the commitment of disability organisations, the concept of disability experienced an important theoretical adjustment.[8] Harsh criticism of the "medical model" of disability, which focuses on physical, sensory and cognitive limitations of the disabled person and therefore on the assumption that they are "ill" and must be cured and rehabilitated (Barnes, 2011; ENIL *et al.*, 2015) led to the "social model"[9] of disability (WHO & WB, 2011), which focuses instead on the economic, social and environmental barriers they encounter.

> The social model of disability has its roots in the text *Fundamental Principles of Disability* (UPIAS & DA, 1976), which contains the results of a meeting between activists of the *Union of the Physically Impaired Against Segregation* and the activists of the *Disability Alliance*. The text maintains that disability is not caused by the bodies of the disabled persons but by society: disability is defined as a form of "social oppression" equal to that suffered by women, ethnic minorities and homosexuals.

A crucial role in overcoming the medical model of disability was played by the World Health Organization through the ICF (WHO, 2001), which proposed a fusion of the medical and the social disability model (Barnes, 2011), defined the "biopsychosocial model."

The biopsychosocial model of disability principles can be summed up as follows (WHO & WB, 2011):

- Disability is complex, multidimensional, dynamic; it is part of the human condition because almost everyone, at some point in their lives will experience temporary or permanent disabilities;
- The medical approach (individual) and the social approach (structural) to disability should not be interpreted as contrasting but rather as complementary;
- Generalisations about "disability" or "persons with disability" can generate misunderstandings since they do not represent the variety of individual conditions;[10]

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[8] For a critical analysis of the historical evolution of the concept of disability and of how to understand the disabled, see Canevaro & Goussot (2000); Ryan & Thomas (1987); Barnes (1997); Stiker (1999).

[9] According to Barnes (2011), the expression "social model" was coined in 1981 by Mike Oliver, a disabled British activist and sociology professor.

[10] According to the WHO & WB (2011), while the stereotyped views of disability refer only to certain disabled groups (for example people with motor disabilities, the blind, the deaf, etc.), disability actually embraces a much wider range of cases (for example a child born with cerebral palsy; a young soldier who loses a leg by stepping on a landmine; a middle-aged woman with serious arthritis; an elderly person suffering from dementia, etc.).

- Although it is true that disability brings a condition of disadvantage, not all people with disabilities are disadvantaged in the same way, since other personal factors can have a significant effect on disability: gender, age, socio-economic status, sexual orientation, culture, and ethnic origin;
- Disability is connected to poverty in a bidirectional manner:[11] disabled persons are more likely to experience economic disadvantages than others and poverty can bring health problems associated to disability;
- Disability is strictly connected to human rights; due to their condition, disabled persons often experience forms of inequality including (1) disparity in access to healthcare, employment, education, political participation; (2) violation (for example abuse, prejudice, disrespect); (3) denial of autonomy (for example forced sterilisation, confinement in institutions against their will, judicial interdictions).

Thus, the biopsychosocial model defines disability as the result of a complex and dynamic relationship between a person's *state of health* and the *individual's contextual factors*. The latter can be of both a *personal* and an *environmental* nature.

> *Personal factors* include the individual's personal background and other characteristics unconnected to their state of health: gender, ethnic origin, age, physical condition, lifestyle, habits, education level, capacity to adapt, social background, training, profession, past and current experiences, general behaviour models, character traits. *Personal factors* can influence a person's participation in society and can have a negative or positive impact on a disabled person's living conditions. These, however, are not yet classified by the ICF.
> *Environmental factors* are related to the physical and social environment in which the person lives; they are classified in two levels: individual and social. The *individual* level, namely the personal environment of the individual (for example home, workplace and school), includes the physical and material features of the environment in which the individual performs their activities and in which they enter into direct contact with others (for example relatives, acquaintances and strangers). The *social* level, which is to say the formal and informal structures, services and interactions with the community or with society having an impact on people include organisations and services linked to the work environment, community activities, institutional services, communication and transport services, formal and informal networks, laws and regulations, behaviours and ideologies (WHO, 2001).

Today, the biopsychosocial model is universally accepted and promoted by the main international organisations, beginning with the United Nations

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[11] In the European Union, the rate of poverty among disabled persons is 70% higher than average (EUROSTAT, n.d., as quoted by the European Commission, 2010) rates and this is due in part to the limited access the disabled have to employment (European Commission, 2010).

through the CRPD (UN, 2006). Referring to the ICF, the CRPD recognises that disability is not an attribute of the person; it is the result of an interaction "[…] between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others." (UN, 2006: preamble, letter "E").[12]

1.4 Autonomy and Independence

The terms "autonomy" and "independence", often used as synonyms, are actually slightly different. They are intricate concepts influenced by the context of reference.

The noun "autonomy" derives from the Greek αὐτονομία, from αὐτόνομος (autónomos), "having its own laws", composed by αὐτο (*autos*, self) and νόμος (*nòmos*, law). Autonomy is, therefore, "the right or condition of self-government […] of a State, community, institution, etc.", or else "the freedom of the will." (Brown, 1993).

The term "independence" derives from the adjective "independent", partly on the pattern of the French *indépendant*, composed by "in", negation, and "dependent". Independence is therefore the condition of what is independent, in other words, "not dependent or contingent on something else for its existence, validity, effectiveness, etc.", "not influenced or affected by others", "not influenced by others in one's opinion or conduct", "thinking or acting for oneself." (Brown, 1993).

> Whenever "autonomy" is used in the broad sense, the terms tend to assume the same meaning. For example, among the various meanings of "autonomy", Brown (1993) includes "independence", "freedom from external control or influence", "personal liberty"; in the same way, Sinclair (1992) defines "autonomy" as "the ability to make your own decisions about what to do rather than being influenced by someone else or told what to do".

Moreover, in literature about disability, a subtle difference emerges between the two concepts: "autonomy" is generally used in reference to the personal capacity for self-management, in other words to "govern" oneself; sometimes the term slides into the concept of "independence", in the sense of the capacity to express wishes and take decisions regarding one's own life without external restrictions. Reindal (1999: 354) underlines the fact that the notion of autonomy, initially used in the political field to indicate independence from foreign domination or from tyranny, is still interpreted today as "independence and the ability to govern oneself without outside domination". Northway (2011: 80) understands autonomy as "something which

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[12] The CRPD has so far (2018) been ratified by 175 countries, whereas 92 countries, including Italy (2009), have ratified both the Convention and the Optional Protocol.

is fundamental to independence and choice", in other words as a prerequisite for independence.

The following pages describe aspects of "personal autonomy" and "independent living" concepts.

1.4.1 Personal Autonomy

The sphere of *personal autonomy*[13] includes all the abilities required for activities that fulfil the personal needs of the individual who wishes to be a fully-fledged member of society. These abilities include, for example, personal hygiene, dressing, feeding oneself, domestic chores, and leisure (D'Alonzo, 2003).

The meaning of personal autonomy, however, transcends the merely "material" aspect linked to the execution of activities – namely doing – and contributes to the construction of the individual's identity. Personal autonomy therefore plays a fundamental role in the life of every human being.

Personal autonomy is a subjective resource assuming traits and meanings that change according to the individual's physical condition, as well as personal factors such as age, state of health, level of education, cultural background, etc. It is evident, for example, that the concept of personal autonomy assumes a different meaning when referring to a disabled rather than a non-disabled person. Indeed, the presence of a disability can greatly compromise personal autonomy, limiting or even impeding the performance of certain activities and the achievement of a life project. Even if referring only to the disabled person, there are significant differences in terms of personal autonomy among people with various types of functional limitations, ranging someone with cognitive problems to someone with physical or sensory issues (Reindal, 1999; Laurìa, 2016a).[14]

Moreover, the time when the disability occurs has a defining impact on the person and their autonomy as its limitation may emerge from childhood, or suddenly, or gradually, or later in life. All with a completely different effect on a person's life.

Above all, when a disability is severe and the person's capacity to carry out certain activities on their own is non-existent, the actions of the family and social support network take on a central role, in particular those undertaken by the caregiver (Meininger, 2001). Autonomy, indeed, "does not necessarily mean 'doing things without help', nor is it restricted to persons with full cognitive ability. Persons who are dependent on others in various

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[13] For the term "personal autonomy" see also the Introduction.

[14] In this respect, Meininger (2001) observes how in the presence of serious cognitive disabilities the concept of autonomy – understood as the capacity for self-determination – may be difficult to define, since the ability to develop plans, understand the consequences of one's own choices, and ultimately to choose, can be greatly compromised.

aspects of life due to intellectual impairment, cognitive limitations, frailty, disease, or simply ageing or childhood, can achieve autonomy with respect to their expectations and environment" (EUSTAT, 1999: 22).

Autonomy can also be interpreted as a complex result of human relationships, namely reciprocal interactions between one person and others. This is valid for everyone, regardless of their health condition or functional limitations; in fact, no human being can be considered completely "autonomous" since everyone acts in a condition of *interdependence* with others to varying degrees (Agich, 1993; Northway, 2011).[15] From this perspective, personal autonomy is also the result of the relationship between *care receiver* and *caregiver* (Meininger, 2001).

Beyond the aspects linked to the individual and to the family and social environment, the physical environment also has an effect on personal autonomy. It is the physical environment that actually fosters or hinders the person-environment fit process. As stated in the Introduction, since the disabled person has a lesser capacity than the non-disabled to adapt to the physical environment, then this must adapt to their needs and expectations. This is particularly important in the case of severe disabilities.

1.4.2 Personal Autonomy Assessment Methods

Several methods have been established in the health sector for assessing the autonomy of frail and disabled persons in performing certain everyday activities. The methods available today are not specifically related to the physical environment in which the activities take place.

There follows a brief overview of the following assessment scales:

- *Barthel Index*;
- *Impact on Participation and Autonomy*;
- *Functional Independence Measure*;
- *Activities of Daily Living scale*;
- *Instrumental Activities of Daily Living scale.*

The *Barthel Index* (BI) is used for measuring a disabled person's level of self-sufficiency in carrying out ten everyday activities: (1) feeding, (2) chair/bed transfers, (3) personal hygiene, (4) toilet, (5) bathing self, (6) ambulation (or wheelchair), (7) stair climbing, (8) dressing, (9) bowel control, and (10) bladder control. Each activity is scored to quantify the level of self-sufficiency in conducting it and the total gives an overall score of 0 (total dependence) to 100 (total independence) (Mahoney & Barthel, 1965; Shah, Vaclay & Cooper, 1989).

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[15] On the concept of "interdependence" see also § 1.4.3.

The *Impact on Participation and Autonomy* (IPA) measures the disabled person's degree of autonomy and participation in everyday life. It is measured by filling out a form of closed questions regarding the following topics: (1) autonomy indoors, (2) family role, (3) autonomy outdoors, (4) social life and relationships, and (5) work and education. The scores for each question varies from 0 (very good) to 5 (very poor). The questionnaire also investigates to what degree possible limitations to self-determination are seen as problematic when making choices. In other words, when having to decide the manner, time and place for performing specific activities. For this purpose, additional questions address the following issues: mobility (getting around where and when you want); self-care; activities in and around the home; looking after your money; leisure; social life and relationships; helping and supporting other people; paid or voluntary work; education and training (Kersten, 2007; Hammar *et al.*, 2014).

The *Functional Independence Measure* (FIM) assesses self-sufficiency separately from the origin of the disability and the specialised skills required for assessment. The FIM is based on an international standard for measuring disability that analyses the person's need for assistance in connection to eighteen everyday activities, divided into six sectors: (1) self-care (eating, grooming, bathing, dressing upper body, dressing lower body, toileting); (2) sphincter control (bladder management, bowel management); (3) transfer (bed-chair-wheelchair, toilet, tub or shower); (4) locomotion (walk/wheelchair, stairs); (5) communication (comprehension, expression); (6) social cognition (social interaction, problem solving, memory). Every activity is scored from 1 (complete dependence) to 7 (complete independence) and the total score can therefore vary between 18 and 126 (Ottenbacher *et al.*, 1996).

The *Activities of Daily Living* (ADLs) include everyday aspects like bathing, dressing, using the toilet, transferring (e.g.: from bed to chair), continence, feeding (Katz *et al.*, 1963; Katz, 1983; Dunlop, Hughes & Manheim, 1997). The *Instrumental Activities of Daily Living* (IADLs), on the other hand, are everyday activities that require the use of instruments or devices, including use the telephone; shop; handle money; cook meals; perform housework; do laundry; manage transportation; take medications (Lawton & Brody, 1969; Levine *et al.*, 2004). There are several versions of scales that use the ADLs and the IADLS. Generally, 1 point is assigned for each activity carried out autonomously. The overall ADLs and IADLs scores vary from 0 (complete dependence) to 6 (for ADLs) or 8 (for IADLs) (complete independence in all functions).

1.4.3 Independent Living

There are many definitions of "Independent Living" in available literature (see, *inter alia*, Townsley *et al.*, 2010; ENIL *et al.*, 2015). According to the UK's Disability Rights Commission (2002) the expression refers to the fact that the disabled, like all other citizens, are entitled to choose and control, and to enjoy the same freedom, at home, at work and as members of the community. Independent Living does not necessarily imply a condition of self-sufficiency: when necessary, disabled persons will receive care and practical support. The fundamental aspect is that every form of care and support must be based on the individual *choices* and *aspirations* of those who will benefit from them (DRC, 2002, as cited by ENIL *et al.*, 2015).

As also explained by Reindal (1999), in Independent Living literature, the concept of "independence" is based on the concept of "control", understood as the ability to manage one's own life, making choices and taking decisions, even when the material execution of certain physical or intellectual activities are delegated to other people. Independent Living is not so much linked to the individual capacity to carry out a certain activity, but to the capacity to obtain assistance *when* and *how* desired.

> In the words of Adolf Ratzka, director of the Independent Living Institute of Stockholm, "Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation. Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbours and friends take for granted. We want to grow up in our families, go to the neighbourhood school, use the same bus as our neighbours, work in jobs that are in line with our education and interests, and start families of our own. Since we are the best experts on our needs, we need to show the solutions we want, need to be in charge of our lives, think and speak for ourselves – just as everybody else. To this end we must support and learn from each other, organise ourselves and work for political changes that lead to the legal protection of our human and civil rights. We are profoundly ordinary people sharing the same need to feel included, recognized and loved. As long as we regard our disabilities as tragedies, we will be pitied. As long as we feel ashamed of who we are, our lives will be regarded as useless. As long as we remain silent, we will be told by others what to do."[16]

Clearly, the concept of Independent Living is applicable to everyone as all human beings have the right to decide with regard to their own life. Disabled persons, however, encounter many obstacles to the fulfilment of that right, and this limits their freedom to exercise additional rights like housing, education, care, employment. The concept of Independent living is therefore closely connected to the citizen's rights of disabled persons. (ENIL, 1989; Zarb, 2004; Ratzka, 2007; Nussbaum, 2011; Belli, 2014; ENIL *et al.*, 2015).[17]

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[16] From the website <http://www.independentliving.org/> (last access: 01/2019).

[17] In the Strasbourg Resolutions, adopted in 1989 during the first *European Independent Living Conference*, it was affirmed that: "We, disabled people, recognising our unique expertise, derived from our experience, must take the initiative in the planning of policies that directly affect us. To this end we condemn segregation and institutionalization, which are a direct violation of our human rights [...]

The right of disabled persons to Independent Living was established at international level by the CRPD, which recognises "the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices" (UN, 2006: preamble, letter "N"), and in particular "the equal right of all persons with disabilities to live in the community, with choices equal to others". For this reason, "effective and appropriate measures" must be adopted "to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community." (UN, 2006: art. 19).[18]

If the right to Independent Living is not to remain a mere aspiration, a series of conditions must be fulfilled to foster its implementation. First of all, a deep cultural change in society leading to a different approach to disability (Ratzka, 1989; Zarb, 2004; Ratzka, 2007; Belli, 2014; ENIL, 2014; ENIL *et al.*, 2015). In line with the social model of disability – representing the theoretical foundation of Independent living – some scholars underline the fact that even today a disabled person's aspiration to independence is often compromised by hyper-protective or negative discriminatory attitudes toward them.[19] The widespread perception of the disabled as "vulnerable" and "frail" feeds a sort of "culture of dependency" which considers them passive subjects of assistance and care, exempted from responsibility. If this cultural conditioning were to be overcome, it might contribute to spreading a perception of disabled persons as citizens capable of a positive and active contribution to the construction of society (Zarb, 2004; Ratzka, 2007).

On a political level it is necessary to implement coordinated strategies within the various sectors involved (for example economy, education, construction, transportation, labour, social policies, etc.) and aiming to remove obstacles to a full social participation by disabled persons (ENIL *et al.*, 2015). At the basis of each action there should be the recognition of the various needs and solutions connected to the fulfilment of the objective of independence. In this respect it may be worth mentioning the operational

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We firmly uphold our basic human right to full and equal participation in society [...] and consider that a key prerequisite to this civil right is through Independent Living and the provision of support such as personal assistant services for those who need them." (ENIL, 1989).

[18] Note that the right to Independent Living is at the basis not only of Art. 19 of the CRPD ("Living independently and being included in the community"), which expressly recognises it, but underpins the entire text (see ENIL *et al.*, 2015).

[19] For example, during his opening speech at the *European Independent Living Conference*, Adolf Ratzka listed the principles and objectives that underpin Independent Living, and focused attention on the need to "de-medicalise" and "de-professionalise" the approach to disability (Ratzka, 1989). He thought that society had handed the control of the lives of disabled persons over to "disability professionals": doctors, nurses, physiotherapists, occupational therapists, psychologists, rehabilitation consultants, social workers, etc. (see Ratzka, 2007).

framework for support to people with disabilities, based on "seven needs for independent living", identified by the *Derbyshire Centre for Integrated Living* (DCIL) in 1985 (Davis, 1990; Barnes, 2011): (1) Information; (2) Peer counselling and support; (3) Accessible housing; (4) Technical aids and equipment; (5) Personal assistance; (6) Accessible transport; (7) Access to the built environment.

In particular, the issue of housing is central to the right to Independent Living. As already stated above, exercising this right explicitly considers the freedom to choose where to live, with whom to live, and with what form of assistance. This means that if they so desire, disabled persons should be given their own dwelling place within their own community (ENIL, 2014). In the view of the Independent Living Movement, independently of the level of assistance they need, all disabled persons should live in their own home, adequately supported and assisted (ENIL, 2014; ENIL *et al.*, 2015).

Many authors (Ratzka, 1989; Zarb, 2004; Ratzka, 2007; ENIL, 2014; ENIL *et al.*, 2015) note the need for a gradual social and political process aiming to overcome the system of special services "dedicated" to the disabled, including transport and education.[20] This approach points out that residential care facilities for the disabled contributes to their segregation and discrimination, due to two main reasons: (1) the separation of the disabled from their family and social support networks, therefore depriving them of important emotional support, and (2) standardised services offered seldom meet the needs of each individual. Literature shows that disabled persons must have access, at appropriate costs, to barrier-free private housing with adequate accessibility and with all the rights available to other citizens: social housing rent, private rental, housing cooperative, private property (ENIL *et al.*, 2015). The removal of "dedicated" structures and services should be flanked with implementation of accessible community-based services (transport, healthcare, culture, leisure, etc.), adequate for the needs of the disabled who could then make use of them near to their homes, just like other citizens (Ratzka, 2007; Laurìa, 2012a; ENIL, 2014; ENIL *et al.*, 2015).

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[20] Regarding education, in Italy a fundamental stage in the evolution of the regulation concerning the integration of disabled students is represented by Law 517/1977 as subsequently amended and supplemented. The law establishes the abolition of special classrooms, the integration of disabled students in regular classrooms and the introduction in elementary (Art. 2) and middle (Art. 7) schools of special educational needs teachers with the purpose of providing support and carrying out special complementary educational activities for the benefit of disabled students. Law 104/1992, as subsequently amended and supplemented (Articles 12 and 13), reaffirms the right to education and training of disabled persons in schools and universities, and the interventions necessary for the integration in schools of disabled students are defined, with the aim of developing their potential for learning, communication, relationships, and social interaction.

> Regarding the housing needs of disabled persons, Racino *et al.* (1993) identified four key principles: (1) all individuals need housing; (2) housing should be based on individual needs and preferences; (3) public services provided in the various areas of a city should take into consideration the needs of individuals; (4) adequate support should be provided for people to allow them to live in an integrated, and highly personalised housing situation. With respect to the option of having a person with severe disability living in their own home instead of in residential care facilities for the disabled, O'Brien (1994) highlights how it is fundamental to consider the three main aspects of living: (1) the possibility of experiencing a *sense of place* (for example, giving a personal touch to the home, taking care of domestic chores, providing the necessary improvements and repairs to the home, being able to grow vegetables, offering hospitality to friends, neighbours and strangers); (2) the possibility of having *control* (personally or with assistance) of the home and the necessary support for living in it (for example, deciding where and with whom to live and managing one's own money); (3) the possibility of experiencing *security of place*, assuming in a direct way the role of owner or tenant of the dwelling.

A peculiar aspect of Independent Living regards the concept of assistance to disabled persons, so they can perform everyday activities. As previously mentioned, the notion of "independence" does not imply a condition of self-sufficiency in the execution of specific activities, so it is necessary to set aside the approach based on a dependence-independence distinction, since *vulnerability* and *interdependence* are conditions affecting everyone, not just disabled people (Reindal, 1999; ENIL, 2014; ENIL *et al.*, 2015).

> Ratzka (1989) dwells on the concept of *interdependence,* or reciprocal dependence among people whereby an individual uses the knowledge and skills of other people daily to compensate for their own lack of ability or lack of time to undertake certain activities. For example, everyone calls upon artisans or professionals to undertake jobs they are unable to do themselves, or which would require too much time, like repairing a tap or a car. We delegate specific tasks to others, so we have the time and energy we need for other activities: work, social relations, leisure. In other cases, we need the emotional support of relatives or friends (for example to make an important decision), or of their material help for especially demanding tasks, like taking care of small children (see ENIL, 2014).
>
> While some disabled persons are sufficiently autonomous at a personal level to deal with everyday activities linked to primary needs like eating, getting dressed, personal hygiene, etc., the time and commitment required for these tasks can be such that other activities (working, for instance, or a social life, or political activities) are then reduced or hindered. In these cases, the support of others can be fundamental to reduce the time and energy the disabled person invests in taking care of themselves and leaves them free to engage in activities considered more satisfying and significant for their life project (Ratzka, 1989).

When clearly required, care may allow every disabled person to "compensate" an impairment by delegating to others the execution of physical or intellectual tasks they are partially or completely incapable of undertaking alone (Ratzka, 1989).

The most widespread form of care is that provided voluntarily by relatives living with the disabled person, and who often make enormous physical, emotional and economic sacrifices.[21] According to Independent Living Movement activists, however, it is fundamental to ensure that the disabled persons who request a paid *personal assistance* service should receive it. The term "personal" refers both to the role of the disabled person, who must decide the manner, time and place of the assistance provided, and to the fact that the service must be extensively personalised to respond to individual needs (Ratzka, 1989).

This type of support should be available in various forms, according to the level and type of care needed. It can be a service provided occasionally, or at specific times of day, or continuously throughout the day. Service providers can also be of different types: the disabled person should be offered the chance to request staff from outside the family circle or to appoint one or more family members to be the caregivers (ENIL, 1989). In any case, the relationship between *caregiver* and *care receiver* should always be based on the principle of the choice of the disabled person, who should always have the possibility to manage caregiving activities directly, and if necessary to train the caregiver, deciding the activities to be delegated, choosing places, times and specific methods of assistance (Belli, 2014; ENIL, 2014; ENIL *et al.* 2015).

Care should take into account the wishes, aspirations and lifestyle choices of the disabled person, so as to allow them direct involvement in every aspect of life. For this reason, care should not focus only on activities linked to primary needs (such as eating, personal hygiene and grooming), but must offer the disabled a chance to engage in family and social life, and when requested provide support at school and work, and during leisure and travel (ENIL, 1989; Zarb, 2004; Belli, 2014; ENIL, 2014).

1.5 Autonomy at Home

When we speak of autonomy, one of the most important areas of focus is the home environment, which plays a vital role in the human experience and is the core of a significant part of everyday activities. Increasing autonomy at home for the disabled person not only means obtaining positive effects for individuals and their families, but also saving resources for the community in terms of social and healthcare costs, in particular by preventing the risk of injury and the need to move disabled persons to care homes.

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[21] On the subject of the subjective care burden experienced by caregivers, in particular concerning the *Caregiver Burden Inventory* (CBI) (Novak & Guest, 1989), see § 2.3.

The importance of autonomy at home is evident when considering that an essential part of a person's daily activities is based there.[22]

In general terms autonomy at home is not always to be understood in the strictest sense, namely the capacity to undertake domestic activities without the assistance or support of others. For some disabled persons, as already mentioned, such a goal may be entirely or partially impossible. Therefore, autonomy at home should be conceived as a disabled person's prospects or inclination for making their own choices regarding the manner, time and instruments for undertaking activities at home, rather than the capacity to carry out such activities unaided.

Autonomy at home is deeply influenced by subjective elements of a physical, sensory, cognitive, psychological, proxemic and relational nature, and is not a univocally recognised value. A disabled person does not always think increased autonomy in the home environment is necessary; this can also be true for the members of their family nucleus.

Vaičekauskaitė (2007) studied the role of the parents of disabled children, examining their attitude to developing autonomy in their offspring. Lewis (1986) and Hovey (1993) analysed the tendency of some parents of disabled children to postpone or fail to implement the modifications needed to make their children's rooms more accessible, and the deep underlying psychological motivations for this. Anyone promoting autonomy at home for the disabled should be aware of the complex psychological dynamics that may impede it.

> Vaičekauskaitė's study (2007) focuses on the development of autonomy in disabled children from the perspective of parents and on the repercussions of the increase in autonomy in the participation of disabled children in social life. It has emerged that most parents interviewed connected the concept of autonomy to a state of good health and lack of disability, so many parents tended to point out the differences between their children and non-disabled. Research showed that parents would have benefited from adequate support to promote the development of their child's autonomy. The role of social workers and, when applicable, of professional caregivers, in providing support to disabled children for performing everyday activities also appeared fundamental for contributing to development of their level of autonomy.
>
> Lewis's work (1986) highlighted two main causes for parents of disabled children postponing actions for making their rooms accessible. The first was due to practical difficulties such as the lack of time and economic resources for converting the home; inefficient public services; lack of awareness in medical personnel of the issue of architectural barriers at home and their impact on the quality of family life. The second cause was often linked to the parents' subconscious reactions. First of all, the conflict between the wish to have their "dream home" (often corresponding to the stereotype image of their childhood home) and the functional requirements of the child, which require modifications to the home. Then the reluctance to adapt the

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[22] See Introduction.

> dwelling due to their inability to accept the permanent nature of the child's disability. Finally, the wish to distance the family from the "stigma of disability", made even more evident in the event of visible modifications to the exterior of the home.
>
> Hovey's research (1993) confirmed that housing adaptations are often refused by families when they represent the explicit avowal of their child's disability. One family interviewed for the research said that building ramps to improve their son's mobility would be an obvious declaration of the fact that there was a disabled person in the family. The gender and age at which the disability appeared in the child also had an influence on choices, with a greater tendency to carry out modifications in the case of male and older subjects, with the purpose of maintaining a certain degree of autonomy.

Autonomy at home has a profound effect on a person's well-being and the quality of life. For example, in the case of traumatic events or illnesses which occur at some point in a person's life and generate a condition of disability, the recovery of autonomy at home through rehabilitation can be understood as the individual's capacity for returning to what matters for them or what they need in daily life (Arenghi, Cretti & Scarazzato, 2015). It is also evident that an increase in a disabled person's autonomy at home represents a benefit for the entire family nucleus and for any external caregiver present (Cook *et al.*, 1996).

Interventions aimed at fostering autonomy at home for disabled persons and the care and assistance provided by their caregivers can be designed as preventive strategies that avoid or at least delay the institutionalisation namely relocation to care homes, of those with disabilities.[23] These interventions, insofar as they offer the freedom to choose whether to remain in one's own home or to move to a care facility, can also be seen as a way to augment individual capabilities.[24]

Autonomy at home depends mainly on three factors, which influence each other reciprocally and dynamically (Fig. 3):

1. The person;
2. The family and social support network;
3. The physical environment.

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[23] Ratzka (1984), describing the Swedish context, estimated that through adequate adaptations to the homes of the disabled, it would be possible to avoid up to 40% of transfers to care homes, with significant financial savings.

[24] In Capability Approach language, living in a care home and living in one's own home represent two *functionings.* The possibility of choosing between these two functionings is, instead, a *capability.* "Functionings", as Sen (1993: 31) writes, "represent parts of the state of a person – in particular the various things that he or she manages to do or be in leading a life. The capability of a person reflects the alternative combinations of functionings the person can achieve, and from which he or she can choose one collection." See also Nussbaum (2011: 25).

By intervening in an integrated manner on these three factors, the person's level of autonomy at home can be increased.

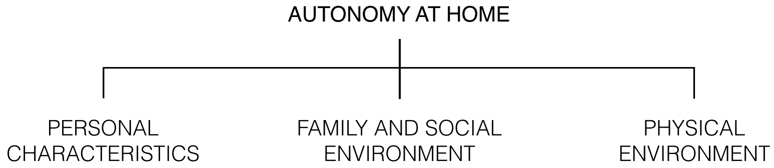

Figure 3 – The three dimensions of autonomy at home.

Of the interventions conceived for the disabled person, the following are particularly significant: (1) adoption of appropriate assistive products aiming to enhance the person's functional performance through the use of specific person-environment "interfaces" (for example, a wheelchair); (2) rehabilitation interventions carried out by specialised personnel; (3) initiatives for the promotion of long-term independent living processes (for example, autonomy at home courses for the blind and the partially sighted). Education for autonomy is an important issue especially in the area of initiatives for disabled children and teenagers, since it provides them with the tools for learning personal autonomy, behavioural and motor skills, assisting them in the process of social inclusion for that stage of their lives when their parents will no longer be able to offer them the necessary support and later, when they die. Whenever required, support initiatives may be implemented, for example by introducing or reinforcing assistance services provided by external figures. As already mentioned, assistance in some cases may help not only in the material execution of specific everyday activities, but also contribute to the fulfilment of personal aims and aspirations.

An efficient *family and social support network* can play a positive role in the disabled person's autonomy at home and in this respect, actions involving relatives and other individuals who provide support to the disabled (for example, professional caregivers, neighbours or acquaintances) can be very fruitful. Moreover, it may sometimes be useful to initiate actions that aim grow the disabled person's social network, for example by promoting participation in groups and associations that organise sports, and cultural, political or volunteer activities, or even through use of digital technologies. For example, by providing appropriate information technology devices – supported by specific training courses – for long-distance multimedia communication (e.g., chat, email, social networks, etc.).

With respect to actions relevant to the *physical environment*, many studies underline the impact of the role of the environment's physical configuration on how everyday activities are undertaken and, consequently, on the level of autonomy at home (see, *inter alia*, Lawton & Nahemow, 1973; Steinfeld *et al.*, 1979; Lawton, 1982; Steinfeld & Danford, 1999; Fänge & Iwarsson, 2005; 2007; Petersson *et al.*, 2009; WHO & WB, 2011).[25] In this respect, it is worth mentioning a research project by Cook *et al.* (1996) that analysed the role of the home environment in the cognitive development of disabled children. The study highlights how the distribution of rooms, furniture, equipment, objects, device controls, room lighting, surface finishes, colour, temperature, etc., influence how activities are performed, facilitating some and limiting others. This research is significant since it clarifies how the quality of interaction with the environment can affect a disabled person's capacity for self-determination and self-esteem.

Questions regarding interventions on the physical environment for increasing the personal autonomy of disabled persons are the focus of this book and will be analysed below.

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[25] The *World Report on Disability* (WHO & WB, 2011: 4) states: "A person's environment has a huge impact on the experience and extent of disability. Inaccessible environments create disability by creating barriers to participation and inclusion."

CHAPTER 2

Housing Adaptation

Housing adaptation plays a key role in improving the autonomy and independence of the disabled at home in terms of daily activities, social participation and usability of spaces. Therefore, it can be thought of as a part of the personal rehabilitation process. Moreover, adaptation help avoid injuries at home and prevent relocation of disabled people to care homes. In this way, housing adaptation policies can also contribute to cutting down social and healthcare costs. The purpose of this chapter is to describe a theoretical approach to housing adaptation tailored to the characteristics of each disabled person and the family and social network available.

2.1 Introduction

The expression "housing adaptation" indicates a coordinated series of design interventions in the home of a person presenting functional limitations and aims to increase their level of autonomy when carrying out everyday activities. A collateral goal of housing adaptation is to make caregiving less stressful and healthier in the long run.

Among the strategies and criteria for housing adaptation, some are particularly important.

Firstly, since housing adaptation is part of a personal rehabilitation process (see Iwarsson & Slaug, 2010), it must aim to be as customised as possible, in other words it must be implemented in accordance with the recipient's accessibility needs and housing wishes. The personalisation of interventions requires the designer to apply a very different approach to the universal method usually applied to collective spaces (public or for public use), in order to increase the degree of accessibility.

Since housing adaptation brings to light a complex series of health factors to be considered, a second requirement is an interdisciplinary approach. To design time-efficient housing adaptations consistent with the needs of the disabled person and within the care, social and physical context where they live, the situation needs to be viewed from health, social and environmental perspectives. An interdisciplinary team must thus be set up as dialogue involving different areas of knowledge and types of experiences can help to provide the most adequate design solutions (combining different – even diverging – aspects) and reduce the risk of errors and misunderstandings which, especially in complex processes, often arise when information passes from one player to another.

Antonio Laurìa, Beatrice Benesperi, Paolo Costa, Fabio Valli, *Designing Autonomy at Home. The ADA Project. An Interdisciplinary Strategy for Adaptation of the Homes of Disabled Persons*, ISBN (online PDF) 978-88-6453-898-3,

The exploration of such a multifaceted reality must necessarily be carried out at the disabled person's home. Here, through discussions with the disabled person and their caregivers (formal or informal), direct observation of the physical and social environment, and the exchange of ideas between the members of the interdisciplinary team, accessibility issues and other useful data for developing design solutions are identified.

These solutions, in addition to existing regulations, must be guided by specific criteria so that the adaptations to be carried out can meet the autonomy needs of the disabled person as much as possible, but also their personal taste and the requirements of relatives and external caregivers.

2.2 Personalisation

Housing adaptations must be conceived to achieve specific activities of daily life (for example, moving from one room to another, fetching objects, turning switches on and off, personal hygiene, interacting with the rest of the family, etc.). The activities considered must be consistent with the person's desires (activities that the person *wants* to carry out), with their needs (activities that the person *must* carry out), and with their personal abilities (activities that the person *can* carry out).[1]

Personalisation is therefore the key element in housing adaptation: it requires solutions correlated to the individual characteristics of the person (functional limitations, age, gender, health conditions, etc.) and to those of the family and social support network.

Additionally, it requires a conceptual approach and accessible design strategies which differ from those usually put in place for a collective space (places, buildings and services that are either public or for public use).

Human-centred design of collective space is usually based on *generalisation,* namely an attempt at a universal understanding of phenomena and tendencies and definition of measures and solutions of a general nature (as well as consistent with the quality of the space in question). When intervening on collective space, Universal Design (Mace, 1985; Mace, Hardie & Plaice, 1991) – which requires products, environments and services to be "usable by all people, to the greatest extent possible, without the need for adaptation or specialized design" (CUD, 1997) – represents the most popular and accepted design methodology.[2] The term "universal", however, is not to be taken literally. Indeed, Universal Design solutions may reveal a wide and varied *grey area* of the population composed of individuals (e.g. people with

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[1] See § 5.2, Data sheet S6, Section S6.3.

[2] Universal Design is the design methodology also suggested as well by the *Convention on the Rights of Persons with Disabilities* (UN, 2006), which (Art. 4, Letter F) encourages member states "To undertake or promote research and development of universally designed goods, services, equipment and facilities".

severe disabilities) requiring specific support measures and devices (Laurìa, 2012c; Arenghi, Garofolo & Laurìa, 2016; Laurìa, 2017b).[3] Awareness of the impossibility (theoretical even before operational) of satisfying the needs of every person with the same efficiency through universal solutions downscales the objective of what can be reasonably achieved through accessible design of collective space: not so much aspiring to define "appropriate" solutions for each individual (which is actually impossible), but rather attempting to define "mainstream products and/or services that are accessible to, and usable by, as many people as reasonably possible on a global basis, in a wide variety of situations and to the greatest extent possible without the need for special adaptation or specialised design." (BSI, 2005).

On the other hand, understanding in as much detail as possible the limits and potential of the various user groups is helpful for getting to know the world and its subtleties, not for changing it. Making collective space more accessible does not mean elevating diversity, but rather "harmonising" it. Collective spaces must be "specific" in order to satisfy specific needs but, at the same time, must *be* and *appear* "generic", so as to be adequate for the widest possible spectrum of people, thus avoiding stigmatisation and prejudice (Laurìa, 2003a) (Fig. 4).

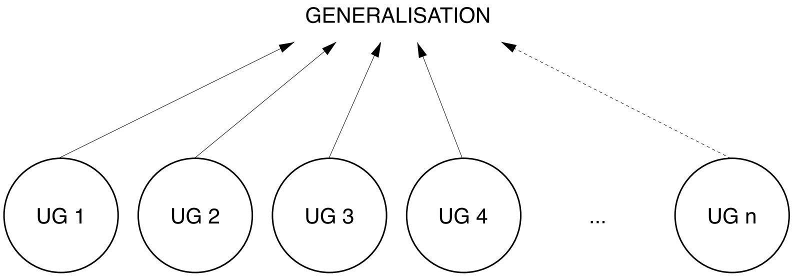

Figure 4 – In the design of human-centred collective space, technical solutions should derive from the harmonisation/generalisation of the needs and expectations of each User Group (UG) in view of contextual factors (climatic, architectural, cultural, historical, regulatory, and so on).

However, when operating in the home environment, generalisations should be set aside for a different approach striving to understand and

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[3] CRPD specifies that Universal Design does "not exclude assistive devices for particular groups of persons with disabilities where this is needed" (UN, 2006: art. 2). Some universally oriented solutions, such as "stramps" (a combination of stairs and ramp) or shared spaces, for example, generate severe issues for people with eyesight problems (see Parkin & Smithies, 2012; Imrie, 2013; Laurìa, 2016a; 2017a).

alleviate accessibility problems that a *defined space* generates for a *specific person* who lives inside a *specific family* and *social context* (cf. WHO, 2001; ISO 9242-11, 2018). The principles of the ICF (WHO, 2001) and of the *capability approach,* which "takes," as Nussbaum (2011: 18) writes "*each person as an end*, asking not just about the total or average well-being but about the opportunities available to each person", can find consistent applications in home environments.

Quoting the *Mishnah* (Tractate *Sanhedrin* 4:5) for the purposes of housing adaptation design, "each person is a world", so the starting point is the analysis of a series of factors influencing well-being to obtain solutions as personalised as possible.

> The uniqueness of each disabled person is perfectly expressed by paraphrasing a famous saying attributed both to Lorna Wing (for autistic persons) and to Tom Kitwood (for dementia patients): "When you've met one person with disability, you've met one person with disability".

Since the home environment emphasizes the *relative nature* of the concept of accessibility, in housing adaptation the same accessibility standards – designed to meet general needs – are not always a goal towards which to strive.

Housing adaptation demands a way of reading and interpreting the habitat which – compared to the challenges arising in conversion of public space – could appear as much simpler and "solider" as they are able to rely on a needs framework that is more easily definable and on more limited and verifiable context data.

Indeed, when speaking about people with severe disabilities this is not the case. Interventions to the homes of the severely disabled require designers or researchers to have specific expertise and skills. First of all, they must be able to listen and have above average empathy. Connecting with the severely disabled and their families, listening to their personal stories, often overflowing with suffering, loneliness, and frustrated expectations, trying to identify with their needs, understanding their life project, can be very difficult and intense, including from an emotional standpoint. It also requires refined judgement skills: two people with the same type of functional limitation may actually have completely different aspirations (as a simple example, one might want to live alone and the other might prefer to stay with their family)[4] and this has obvious implications in terms of design strategies for adapting homes. Furthermore, these aspirations vary with time, as perspective changes as it does for everybody: new work opportunities, changes in the affective sphere and in health, etc. Research conducted

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[4] In Italy, ISTAT surveys (2014) highlighted how difficult it is for the disabled to leave their family context. If 53% of non-disabled persons aged 6-44 live with their parents, the percentage rises to 72% in the case of disabled persons in the same age group.

by Dunn (1987, as cited by Zola, 1989) into a New York City programme (Project Open House) to upgrade the homes of the disabled showed that only two years after interventions were completed, the needs of approximately 40% of these disabled persons had changed. Nonetheless, it is necessary to try to understand the influence of the family and social contexts, and their role in defining solutions (spatial, medical, care, etc.) to address problems. For example, it is necessary to analyse factors such as poverty, loneliness,[5] health conditions, lack of care, the difficulty in learning what rights they have and exercising them, etc.),[6] that are governed by complex and changing mechanisms,[7] and if they interact, they may damage the quality of life of the disabled person and the working conditions of caregivers.

Indeed, the role played by caregivers highlights an aspect that adds further complexity. Under some circumstances (for example, people with severe intellective and/or verbal communication problems),[8] suggested "possible" adaptations are not so much aimed to expand the margins of disabled autonomy in material execution of certain activities at home, but rather at making the work of caregivers more comfortable, safe and efficient. This observation can be interpreted in two ways. On the one hand it proves that the concept of autonomy does not necessarily imply self-sufficiency but represents an aspect of the attitude of the person toward controlling their own life, to request assistance when needed and desired (Ratzka, 1989; Reindal, 1999).[9] On the other, it would seem to suggest a certain hierarchic subordination of the concept of "autonomy" vis-à-vis that of "well-being", in the sense given to it by Sen (1993), of "what a person can do or can be" in relation to their capacity for transforming available means and resources into objectives (see Biggeri & Chiappero Martinetti, 2010). In any case, the concept of autonomy thus defined (to say nothing of well-being) is not consumed in the two-way relationship between the

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[5] In Italy, most disabled persons live alone (36.1%) or in a childless couple (25.3%). A similar situation (37.4% of the total) occurs for persons with severe disabilities (ISTAT, 2016). These data are influenced by the fact that most disabled people are elderly. Indeed, of an estimated 3.2 million disabled, 2.5 million are elderly (ISTAT & Piedmont Regional Government, 2014).

[6] In Italy, the level of education of disabled persons is very low. Most disabled persons over 6 years of age (69.9%) do not possess school diplomas or have only an elementary school diploma (as opposed to 23.9% for the rest of the population) (ISTAT, 2014).

[7] It is important to bear in mind that every person, and therefore every disabled person, simultaneously belongs to different social categories. According to Intersectional Theory (Crenshaw, 1989), these categories interact with each other both at individual and at group and institutional levels (Marchetti, 2013: 134). See also WHO & WB (2011).

[8] For the more general subject of the ability to choose for persons with serious cognitive problems, see Nussbaum (2011: 31 et seq.).

[9] See § 1.4.3.

person and the environment but is open to additional components. Since the caregiver is a *resource* (often essential) for a disabled person, the aim of housing adaptation, when necessary or possible, must address not so much the relationship between the *disabled person* and *environment* as between the *disabled person-caregiver* and *environment* combination. To factor the caregiver into the reading of the housing context means considering their problems as well, and the stress (objective, psychological, physical, social, emotional) they endure.[10] In this respect, it is necessary to consider two additional aspects that can influence both the acquisition of information and the answer in terms of design. First of all, the caregiver may or may not be a family member, a friend or enjoy an affective relationship with the disabled person. In other words, they may be a relative, cohabitant, neighbour or friend of the disabled person, or they may be a paid or volunteer outsider providing care and assistance. Secondly, it is important to note that the presence of a severely disabled person in a family nucleus conditions the existence of every other member. As a consequence, family care is often a combined effort with each member offering support to the affected relative with levels of commitment and intensity that can vary enormously (Fig. 5).

In conclusion, it must be acknowledged that each will for living conditions, needs, and what they expect from the processes for transformation of their habitat, and more generally, as a consequence of their aspirations. Consequently, housing adaptation becomes a “complex” activity that requires a holistic approach (see Hamilton, 1981; Oswald *et al.*, 2007). Every intervention may have different aspects and follow different paths depending on the specific details of the inter-relationship between the disabled person (and their caregiver, when appropriate) and the physical, family and social environment in which they live. It would be naive to believe this activity could be relegated to a merely “technical” dimension. More specifically, it could be said that although the “design solution” is inevitably “technical”, the research that underlies it, nourishes it, must necessarily be based on a kind of Humanism rooted in the philosophy of Protagoras of

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[10] As far as the figure of the caregiver is concerned, it is worth mentioning the *Caregiver Burden Inventory* (CBI), a research tool that aims to assess the subjective care-related burden experienced by the caregiver (Novak & Guest, 1989). The CBI is a multiple-choice questionnaire filled out by the caregiver, which explores five different dimensions of the care-related burden: (1) *time-dependence burden*, which regards the time the caregiver must devote to the person in their care; (2) *developmental burden*, related to the sense of failure experienced by the caregiver, relative to their own expectations and hopes; (3) *physical burden*, which is related to the caregiver’s physical stress and to their perception of their own state of health; (4) *social burden*, which refers to the presence of role-related conflicts of the caregiver in their work and family spheres; (5) *emotional burden*, which concerns the negative feelings the caregiver experiences vis-à-vis the care receiver.

Abdera, which believes that "the human being is the measure of all things" and must therefore consider the specific physical, cultural and social conditions surrounding the disabled person in their environment.

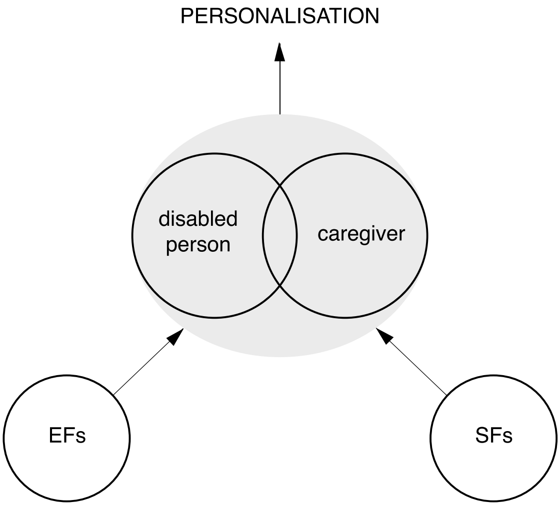

Figure 5 – In projects for adapting the homes of the severely disabled assisted by caregivers, the accessibility solutions should derive from the analysis and interpretation of the needs and expectations of the disabled person-caregiver pair in the light of environmental (EFs) and social (SFs) factors.

2.3 The Interdisciplinary Nature of the Approach

Health is the result of a wide range of personal, social, economic and environmental factors (determinants)[11] (WHO, 1998) and of interconnected variables. Thus, in order to attempt to overcome reductionist approaches and to recompose the singularity of a life project when assessing a person's state of health, it is vital to aim for integration of different types of knowledge and affirmation of work methods that are more consistent with human complexity (Fig. 6).

It is evident that the multidimensional character of autonomy at home (determined, as already mentioned, by the triad: personal characteristics,

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[11] On the determinants of health, see Maciocco (2009). For a more extensive reflection that looks at the unequal distribution of health within society (determinants of inequality in health), see WHO-CSDH (2010).

physical environment, and family and social environment) dictates the need for a *holistic approach* to the issues and for the contribution of a range of types of knowledge, in accordance with an interdisciplinary, integrated and coordinated approach. Physicians, care workers and experts in accessible design should cooperate in promotion of the person's autonomy (see Arenghi *et al.* 2015). Depending on the case under examination and on the adaptation solutions considered, the engagement of additional expertise might be necessary, including electronic engineers, neuro-psychiatrists, physiotherapists, occupational therapists, psychologists, sociologists, etc. Every professional should conduct an in-depth analysis of the specific details of the case for their own area of expertise, connecting with others while focusing on the common objective: increasing autonomy at home for the disabled person.

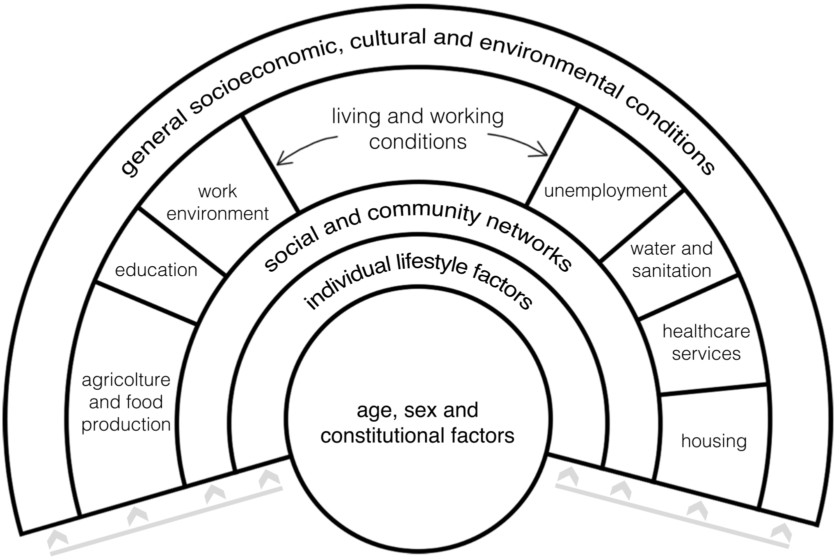

Figure 6 – Determinants of health. From the inner circle, which shows the person's biological characteristics (non-modifiable determinants), the diagram moves on to determinants which can be corrected and or changed (modifiable determinants). [Adapted from Dahlgren & Whitehead (1991)]

In the interdisciplinary approach a cognitive exchange takes place, whereby, as Jean Piaget wrote, the "collaboration entre disciplines diverses ou entre des secteurs hétérogènes d'une même science conduit à des interactions proprement dites, c'est-à-dire à une certaine réciprocité dans les échanges, telle qu'il y ait au total enrichissement mutuel." (Piaget, 1974:

167). This should offer everyone the chance to modify their initial opinion, raise awareness, reconsidering technical questions and attitudes that become axiomatic, often out of habit.

However, integrated interpretation of interaction between the disabled person and their home environment (physical, family and social) still presents a difficult challenge. It is well known that to "integrate" is always more difficult than to "separate". To negotiate one's own beliefs and to harmonise different languages is a difficult testbench and requires the various players involved to adapt in terms of values and a sincere willingness to listen. For example, it is important to overcome the obstacle of field jargon which betray the deep-rooted esoteric tradition of preferring to protect knowledge rather than disseminate and share it (Laurìa, 2008).

2.4 Field Data Production

To identify the most appropriate adaptations for increasing the level of autonomy at home, an in-depth on-site assessment must be planned, to establish the characteristics of the person in their home environment, compliant with the approach proposed by the ICF (WHO, 2001). The needs and expectations of the person must be ascertained in relation to the activities compatible with their overall functional limitations.

This information should be collected through a site survey conducted by an interdisciplinary team at the disabled person's home and using appropriate methods of investigation. In particular, an in-depth analysis of the features of the physical environment must be carried out in relation to the characteristics of the disabled person, their aspirations, their family and social support network, and the activities the person can or wants to carry out at home. The study of personal characteristics must begin by collecting general information such as age, gender, type of disability (physical, sensory, cognitive, multiple), severity of the disability. The next step proceeds to identify the *needs* and *expectations* of the person and assess the *abilities* that the person has in relation to the activities to be carried out within the home environment. It is the specific task of the various professionals involved in the analysis of the needs to illustrate useful information so that the disabled person and – when applicable – their family nucleus can assess needs, identify priorities, define aims and then make the necessary decisions about the modifications to be implemented (see Cook *et al.*, 1996).

During the home environment assessment stage, *accessibility issues* must be identified. These can be classified as two categories: (1) elements present that prevent or impede the carrying out of certain specific activities ("architectural barriers"); (2) elements that are absent yet could facilitate the execution of certain activities, thus contributing to enhance personal autonomy ("facilitators") (WHO, 2001; 2013; Laurìa, 2012a; 2014a). Both the presence of architectural barriers and the absence of facilitators must be analysed in connection to the functional limitations of the disabled person and the assistance they require. For example, an existing bathroom that is too small to be used comfortably by a quadriplegic person in an electric wheelchair and their caregiver is considered an architectural barrier. Conversely, a mobile hoist, still to be installed, to achieve safe transfer of the disabled person from the wheelchair into the bathtub is a facilitator.

One of the aspects worth considering from an interdisciplinary point of view is the stability of the functional clinical situation or its possible evolution (prognostic assessment). Foreseeing possible changes to the patient's health and the timeframe in which they may become manifest will make it possible to identify solutions ensuring some degree of *flexibility*.[12]

Furthermore, it must be kept in mind that whenever disability presents itself in adult life, the moment when the disability appears and the speed with which it makes its effects felt will usually have important repercussions on the person's capacity to adapt to the environment (Morena, 2015). For example, in the case of sudden blindness caused by a traumatic event, the person's capacity of adaptation to the new situation will generally be lower than that of blindness that develops gradually, possibly caused by a progressive illness (for example, diabetic retinopathy or glaucoma).

To establish the most complete picture of the person it is also necessary to enquire into other areas, for example asking about personal desires and aptitudes. As already mentioned, two people with the same functional limitations could have completely different life projects as far as their affective, social, educational, professional or leisure spheres are concerned.[13]

To understand a person's background fully it is important to look also at details of the family and social support network. Adaptations will only work if the disabled person is considered in connection to the figures who help them to perform everyday activities. This type of approach is fundamental not only because in situations of severe disability actions to put in place might be addressed mainly or solely at making the caregiver(s) tasks easier,[14] but also because the presence of other people when carrying out an activity can have an impact on the size and configuration of spaces and must thus be carefully assessed from a design standpoint.

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[12] Italian Standard UNI 8289:1981 makes *flexibility* a requirement for usability. It is defined as "aptitude of spaces for transformation and with scope for change in the needs of users through time". This definition of flexibility is very similar to that of *adaptability* laid down in Art. 2 Section I) of Italian Ministerial Decree 236/1989, which states: "adaptability is understood as the possibility through time to modify built space at a limited cost, with the purpose of rendering it completely and easily usable also by people with reduced or impeded motor or sensory capacities."

[13] See § 2.1.

[14] *Ibidem.*

2.5 Design Solutions

Once the data acquisition phase is concluded, the most appropriate solutions can be defined for housing adaptation. These solutions fall into three areas of action:

1. The building;
2. The furnishings and everyday use equipment;
3. The plant engineering and the assistive and home automation technologies.[15]

The proposed solutions should be based on the interdisciplinary wisdom derived from field data[16] and since they are for environments for private use, they should tend toward maximum personalisation.

The design approach should aim to make the most of the disabled person's residual capacities in the execution of specific activities while also turning the home into an "enabling" environment (Laurìa, 2014a). Indeed, spaces, equipment and installations play a central role in exploiting the person's abilities. The solutions identified must therefore allow the person to obtain the maximum level of autonomy.

Furthermore, the home can be the preferred environment for rehabilitation activities and of course this makes it necessary to call upon the collaboration of medical professionals.

The solutions to be carried out must be classified according to *levels of priority* based on the potential levels of autonomy at home they may achieve, so that adaptations with bigger impact on autonomy can be undertaken before others.

As said earlier, solutions must be devised so they can evolve with the needs and clinical picture of the disabled person. In other words, solutions should be such that they can adapt to the person's future over a reasonably long term. This may entail, for instance, the adoption of reversible solutions involving dry assembly methods.

Once the proposed adaptations have been carried out, they may have a deep influence on the life of the disabled person and of the family nucleus, establishing a new way of undertaking certain activities or reorganising care activities in the home environment. For example, following adaptations that lead to a significant increase in the person's autonomy, a caregiver may no longer be required for specific activities. These aspects should be carefully assessed when deciding solutions, and always taking into consideration the person's voiced and unvoiced wishes, as well as their habits.

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[15] This area of action includes both the traditional technological installations of the dwelling and the I.T. systems and devices that aim to improve the level of autonomy at home of the severely disabled.

[16] On this issue see Introduction and § 2.2.

There should be special attention to obtaining aesthetically pleasing solutions when possible to avoid stigmatising disability. It is best to avoid solutions and products with a "hospital" appearance, or only for the disabled, should be avoided (see Laurìa, 2003b). This attention – as Lewis (1986) points out – can contribute to making it easier for the person and their family nucleus to accept adaptations to their home.

The interfaces for assistive and home automation technologies should be as user-friendly as possible to make them easier and quicker to learn to use. Interfaces that are too complex could confuse the user and that leads to a refusal to use the proposed systems. Placing the *person at the centre of the project* means that making suggested technological solutions simple and easy to use and understand; it also means that the advantages they can bring to daily life must be clear.

> In the European context various projects have been promoted in recent years aiming to enhance the quality of life of disabled and elderly people through the use of *assisted living* and *active living* technologies. Among these it is worth mentioning the *Active and Assisted Living* (AAL) – *ICT for Ageing Well* programme, within the scope of the Horizon 2020 programme, for funding projects to enhance quality of life of the elderly through the use of *Information and Communication Technologies* (ICT). The initiative *Make it ReAAL,* linked to the AAL programme, aims to promote standards, guidelines and open platforms for inter-operational solutions in the fields of *assisted living* and *active living.* Also falling within this remit is the open software platform, UniversAAL IoT, which provides solutions for the integration and interoperability of AAL services and promotes an innovative approach to the issue of the technical and semantic interoperability of systems.[17]

Last but not least, the disabled person and – when applicable – their family nucleus must be adequately informed about the possibility and performance of the proposed systems, devices and services. Following the implementation of the interventions, a support action may be necessary to ensure the proper use of the adaptation. Above all, for technological systems with some degree of complexity personalisation and learning should be scheduled.

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[17] Information obtained from *AAL - Active and Assisted Living programme - ICT for Ageing Well* (<http://www.aal-europe.eu/>), and from *UniversAAL IoT* (<http://www.universaal.info/>) (last access: 01/2019).

SECTION II

The ADA Project

CHAPTER 3

Stakeholders and Beneficiaries

In outlining the structure and contents of the ADA Project several specific aspects had to be taken into consideration: its experimental nature; the overlapping of a scientific research project with an administrative procedure that envisaged the delivery of a service and a grant; the number of stakeholders and agencies involved; and – last but not least –the characteristics of the beneficiaries, who are severely disabled.

In such a multifaceted, complex scenario, to achieve the proposed goals and ensure the quality of the service provided, it was necessary to construct a methodical and sufficiently flexible process, capable of governing complexity while facilitating the collaboration of the players involved, allowing them to operate in synergy to make the most of their specific skills.

3.1 Implementing Agencies

The ADA Project is the result of a coordinated action involving many stakeholders with different functions, expertise and administrative and territorial bodies. It is quite a complex challenge to achieve successful collaboration between these subjects but it is crucial for bringing home the required results. This section describes the organisational structure that served as a backdrop and made possible methodical development of the phases of the ADA Project later described in detail in Chapter 4 of this book.

3.1.1 Tuscany Regional Government

Tuscany Regional Government, and in particular the General Office for Citizen Rights and Social Cohesion – Social and Healthcare Integration Policies Sector (*Direzione Generale Diritti di Cittadinanza e Coesione Sociale – Settore politiche per l'integrazione socio-sanitaria)*, is the agency that promotes the ADA Project.[1] Tuscany Regional Government provided funding, both of the organisational and operational structure, and for implementation of the interventions, through contributions to the health districts.[2] Tuscany Regional Government also defines and guarantees compliance with all general criteria referred to the application of the project throughout Tuscany in order

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[1] The ADA Project was funded in two consecutive phases with 900,000 euros assigned to grants for participants and approximately 250,000 euros to cover the cost of research, design and administrative and operational management of the project.

[2] See note 3 of the Introduction.

Antonio Laurìa, Beatrice Benesperi, Paolo Costa, Fabio Valli, *Designing Autonomy at Home. The ADA Project. An Interdisciplinary Strategy for Adaptation of the Homes of Disabled Persons*, ISBN (online PDF) 978-88-6453-898-3,

to ensure all the region's inhabitants are ensured equal conditions of access to the service offered. To this end, Tuscany Regional Government approved specific Guidelines that defined the development of the entire implementation process and directed the drafting of the call for applications at local level.

3.1.2 Tuscany Regional Health District

Following the approval of the Guidelines, in November 2016 Tuscany's thirty-four health districts[3] call for applications drafted by the regional administration in collaboration with the University of Florence Research Group was also approved.[4]

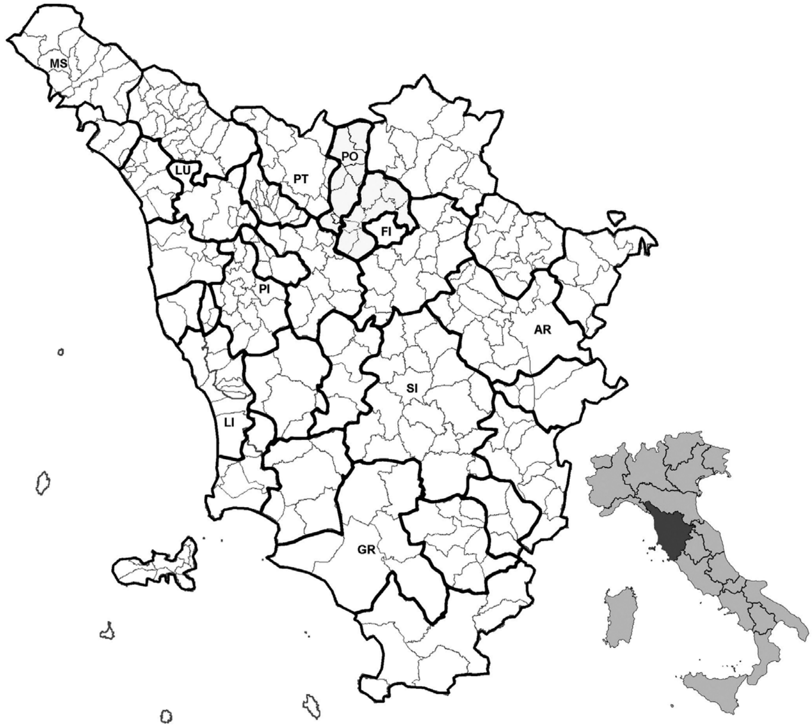

Figure 7 – Tuscany's thirty-four health districts (until 2017). In the bottom right corner: Tuscany's location on the Italian peninsula.

Health districts are the regional structures tasked with managing the ADA Project at local level. The actions each puts in place within their own district constitute a central part of the project. These actions can be summarised

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[3] For the reduction of Heath Districts from 34 to 26 in 2018, see note 2 in the Introduction.

[4] See § 3.1.4.

thus: (1) receipt of regional funding; (2) publication of a call for applications for participating in the project, compliant with regional Guidelines; (3) promotion of the project among potential participants; (4) appointment of the members of the Multidisciplinary Assessment Units (*Unità di Valutazione Multidisciplinari*, UVM/UVH)[5] assigned to the project's implementation phases; (5) participation of appointed personnel in the site surveys to the homes of the disabled and drafting of the accessibility recommendations; (6) assessment of grant applications and distribution of assigned resources to participants compliant with procedures defined by the call for applications (Case Assessment); (7) distribution of grants to entitled participants; (8) support in managing organisation and administration processes.

Given the importance of these tasks, it must be highlighted how these territorial structures represent the main link through which the regional policies and the goals connected to them can be transformed into concrete and efficient actions destined to the beneficiaries of the ADA Project. For this reason, from the onset, a key role was attributed to the capacity of the promoting agency (Tuscany Regional Government) and, to a lesser respect, to that of the other coordinating entities (Regional Accessibility Centre and University of Florence Accessibility Lab) to properly involve and motivate the managers and personnel of these regional structures, so as to ensure their active participation in the Project. Without a close involvement of health district officials, there was a great risk that the ADA Project would be perceived as an additional burden to the usual workload, which would have undermined its possibility of success and compromised the level of quality of its interventions.[6]

A single health district – the "Società della Salute Fiorentina Nord Ovest"[7] – was selected by the Regional Government and tasked with the role of administrative management and coordination of the ADA Project both in the pilot phase and in its extension to regional scale. On behalf of Tuscany Regional Government, this health district established and managed the cooperation agreements with the University of Florence's Architecture Department and

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[5] As defined by Tuscany Regional Government Law n. 66/2008, Multidisciplinary Assessment Units (UVM) are the basis of the "multi-dimensional personal assessment model". Each UVM comprises, as a minimum, a district physician, a social worker and a nurse. This composition may be supplemented by including the GP of the person assessed, medical specialists and other operators considered necessary for defining the Personalised Assistance Project (PAP). The acronym UVH is not part of regional legislation and will usually refer to a specific UVM commission for disabled persons.

[6] This risk was mentioned several times during meetings with health district executives to discuss ADA management methods. Aware of the sheer difficulty of communicating the value of such an innovative project across quite different territorial contexts, the aim to involve heath district personnel as much as possible oriented many of the project's planning actions.

[7] For the difference between health districts and *Società della Salute*, see note 3 in the Introduction.

with the Institute of Science and Technology of Information of the National Research Council of Pisa.

3.1.3 Tuscany Regional Accessibility Centre

Within the ADA Project, the Regional Accessibility Centre[8] (*Centro Regionale per l'Accessibilità* – CRA) was tasked with assisting the health districts and other agencies involved from an organisational and logistic standpoint.

The CRA coordinates ADA Project promotion, educational and information activities, organises site surveys across regional territory, keeps records of activities of interdisciplinary work groups operating in the various health districts, and ensures procedures are standardised at regional level. Finally, it has the task of managing any issues arising during the entire process.

3.1.4 Florence Accessibility Lab Interdepartmental Research Unit

The scientific coordination of the University of Florence Accessibility Lab (FAL) Interdepartmental Research Unit[9] is at the underpinning of the ADA Project. The research, theorganisation of contents derived from accessibility and sociology scientific expertise, the definition of procedures and tools used in the project, and the coordination, monitoring and sharing of the various phases with the other partners, as well as the assessment of results revolve around the FAL.

For the implementation of these tasks, FAL's scientific coordinator ("Principal Investigator") established and runs a research group composed of two architects with expertise in environmental accessibility and a sociologist who is an expert in built environment and evaluation. This research group designed research methodology and defined its operating tools. It also offered training and support to seven additional architects[10] who worked with the interdisciplinary work groups[11] established in every health district in Tuscany to put in place the project's implementation phases.

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[8] Until 2017 the name of the *Regional Accessibility Centre* was "Regional Centre for Information and Documentation on Accessibility" (Centro Regionale di Informazione e Documentazione sull'accessibilità – CRID). For information on the CRA, see <http://open.toscana.it/web/toscana-accessibile/cra-centro-regionale-accessibilita> (in Italian; last access: 01/2019).

[9] For an overview of FAL Research Unit past and present activities, see: <https://www.dida.unifi.it/cmpro-v-p-457.html> (last access: 01/2019).

[10] These architects (Chiara Angioli, Enrico Cibei, Lucas Frediani, Giordana Gregori, Marco Mariotti, Nadia Recca and Lulghennet Teklè) were selected through a public call for applications made by the University of Florence Department of Architecture in December 2016, which garnered a total of seventy-two candidates from all over Italy.

[11] See § 3.2.

Figure 8 – The University of Florence Accessibility Lab Interdepartmental Research Unit staff who worked on the ADA Project at Palazzo Vegni, Florence. From the left: Antonio Laurìa (principal investigator), Junik Balisha, Beatrice Benesperi, Fabio Valli and Paolo Costa.

3.1.5 The "A. Faedo" Institute of Information Science and Technology

The "A. Faedo" Institute of Information Science and Technology (ISTI) of Pisa's National Research Council (*Istituto di Scienza e Tecnologie dell'Informazione, Consiglio Nazionale delle Ricerche* – CNR) and, in particular, personnel from the *Human Interfaces in Information Systems Lab* and the *Signals and Images Lab*,[12] worked with University of Florence personnel to identify and define housing adaptation solutions regarding assistive and home automation technologies.[13] This collaboration included both

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[12] For information on the activities of the ISTI-CNR, see: <http://www.isti.cnr.it/> (last access: 01/2019).

[13] During the ADA Project pilot phase ISTI-CNR personnel also worked to validate tools developed by the University of Florence Research Group and joined in the assessment actions for regional funding assignment.

organising training for the architects participating in the interdisciplinary work groups (to provide them with the contents and knowledge necessary for them to address autonomously the simpler cases in terms of assistive and home automation technologies during site surveys) and offering them dialogue and support about these specific fields when drafting the accessibility recommendations for the more complex cases.

3.1.6 The Learning and Communication Aids Labs

The ADA Project contemplates the involvement of Tuscany Regional Government's *Learning and Communication Aids Labs* (*Laboratori Ausili per l'Apprendimento e la Comunicazione* – LAAC)[14] network. The various professions present in the LAAC and their experience in providing personalised solutions to disabled persons in the field of assistive products, including the sector of assistive technologies, represent an important resource for the ADA Project. A resource in some respects complementing that provided by the ISTI-CNR.

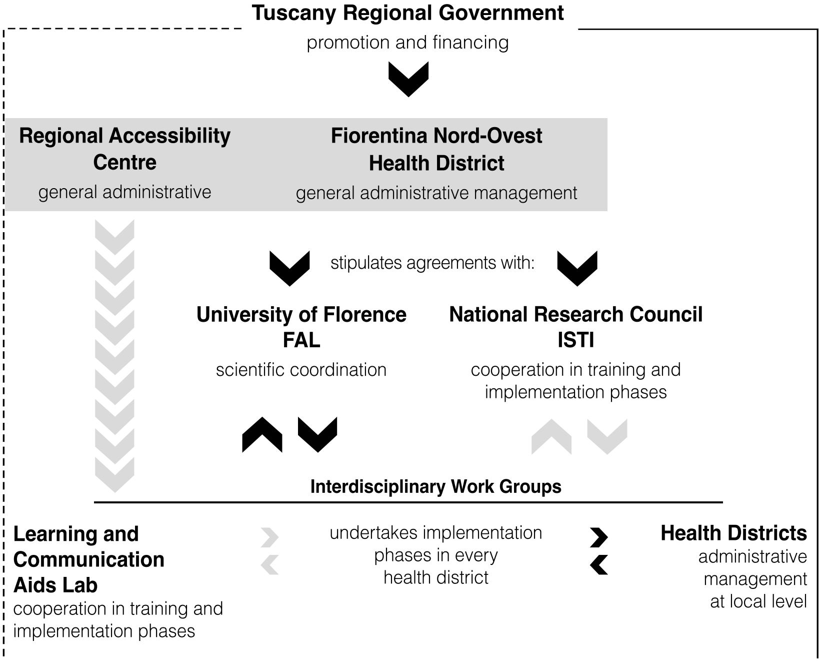

Figure 9 – Roles and tasks of ADA Project players.

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[14] For further information on Tuscany Regional Government LAAC tasks, see: <http://open.toscana.it/web/toscana-accessibile/laboratorio-ausili> (in Italian; last access: 01/2019).

LAAC members participated in training architects operating in the interdisciplinary work groups, illustrating the services provided and laying the foundations for future collaborations in the field of technological support and solutions whose use aims to enhance personal autonomy and communication and learning functions.

3.2 Interdisciplinary Work Groups

An Interdisciplinary Work Group (henceforth work group) was set up in each health district to put in place the ADA Project.

The interdisciplinary approach[15] adopted by the ADA Project is based on the operating methods that Tuscany Regional Government social and healthcare services operators have pursued for some time via the *Multiprofessional Integration Model*. This model is based on assessment commissions (Multidisciplinary Assessment Units – UVM/UVH) whose "basic" configuration envisages the presence of a district physician, a social worker and a nurse. When necessary, these commissions can include other medical professionals (like specialist physicians). In this way a procedure and common language is established for assessment and care of every disabled person and their families, using the different knowledge, expertise and tools brought by each of the professions involved.

Thanks to the presence in the various work groups of professionals from fields other than social and healthcare services, the ADA Project was able to make another step forward in the multidimensional assessment of the disabled person. The introduction of the "environmental" component in personal assessment resulted in an improvement in fact-finding and the ADA Project's consequent adoption of the biopsychosocial model of disability.

Within the ADA Project, work groups are always composed at least by three people:

1. A physician from the health district, preferably chosen from the corresponding Multidisciplinary Assessment Unit;
2. A social worker from the health district, preferably chosen from the corresponding Multidisciplinary Assessment Unit;
3. An architect with expertise in accessibility.

Healthcare contributions aim to understand the disabled person's health conditions and their functional limitations. These assessments are conducted mainly by physiatrists.

The contribution of social services expertise in needs assessment focuses on observation of the person in their family/social context, on the features

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[15] See § 2.2.

of any social support network present, as well as on the recognition of existing social resources and the possibility of reinforcing them.

The environmental accessibility aspect aims to highlight any conflict the disabled person faces in the home environment and then identify possible design solutions to expand autonomy for conducting activities at home while improving assistance and care tasks provided by any caregiver/s.

> Although this plurality of perspectives initially generated communication difficulties among the various subjects, it soon stimulated the establishment of a natural debate leading to a constructive atmosphere and a positive mutual influence across the various fields of knowledge. Interdisciplinary collaboration proved to be an efficient choice not only for deciding intervention methodology, but also for achieving objectives in terms of the quality required by the ADA Project. For example, awareness of the degenerative process of certain pathologies involved all work group members in defining design solutions that would adapt over time. This result would not have been possible using a sectorial approach.

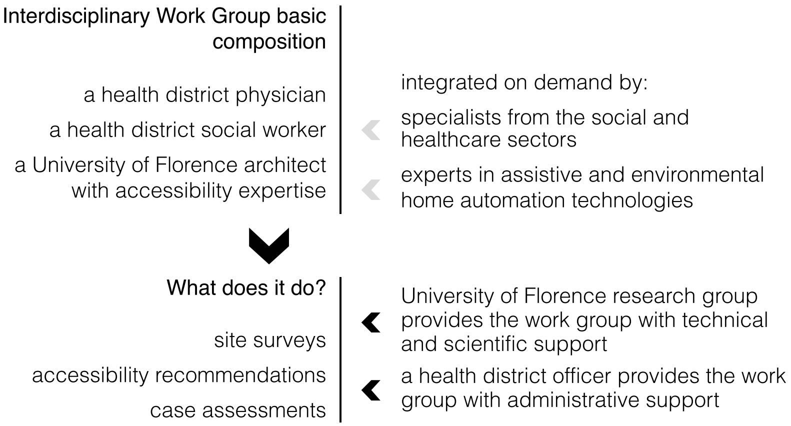

Figure 10 – Interdisciplinary work groups: composition and tasks.

When needed, additional professional figures ("external experts") may join the work group to address cases with specific profiles. These figures belong to the social and healthcare sectors (for example, paediatric neuro-psychiatrists, ophthalmologists, psychologists, etc.), as well as to those concerning assistive and home automation technologies and personalised help. External experts are thus the "variable" component of the work groups.

External experts can intervene in site surveys but also in drawing up the accessibility recommendations, to assess their efficiency and improve proposals. In some cases, the inclusion of external experts in site surveys may be decided during preliminary work group meetings, on the basis of an analysis of the profiles of the disabled persons participating in the project. This is especially valid for experts from the health, social services and aids sectors, whose involvement is also facilitated by the fact that they are already health district staff. In the case of experts from the assistive and home automation technologies sectors, however, their involvement is decided on the basis of site survey results and is needed for drawing up the accessibility recommendations.

Finally, in each health district, project implementation is also supervised by a member of the administrative staff. The contribution of this figure is especially significant during the initial project phases (definition of the call for applications, management of participant data, ensuring compliance of requisites for participating in the project) and at the end (administrative control of intervention proposals, distribution and delivery of grants).

Work group members were all trained in data collection and administration procedures at the beginning of the project.[16]

3.3 Beneficiaries of the ADA Project and Requirements for Participation

The ADA Project was activated by Tuscany Regional Government through two calls for applications. The first, in April 2015, was for the project's pilot phase and limited to just two health districts; the second, which involved all regional health districts was published in November 2016.

To be able to take part in the project, at the date of application the disabled person had to meet the following requirements:

1. Certified as severely disabled compliant with Italian Law 104/1992, Art. 3, Para. 3;
2. Aged between 6 and 65;
3. Resident in the health district and in the home for which a site survey and accessibility recommendations service were being requested.

> There had been a proposal to set no upper age limit at 65 years for project applicants. Although it is true that age usually aggravates an existing disability, in a larger number of cases age itself brings disability and this is reflected in the number of disabled persons in the older age range (see ISTAT, 2014). Moreover, it is precisely the link between disability and old age that makes it so complex to distinguish between the various levels of infirmity among elderly people. At the end of the day, however, bureaucratic and administrative hurdles prevented the elimination of the 65-year age limit.
> The requirement of residence derives from the intention to orient provision of the service to homes where beneficiaries live on a regular basis, thus helping in situations of greater need.

For those who wish to obtain a grant from the Regional Government in addition to the site survey and accessibility recommendations service, there

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[16] See § 4.2.

is a further requirement, which is to prove that the family unit's income does not exceed 36,000 euros, checked by the *Indicator of Equivalent Economic Situation* (*Indicatore della Situazione Economica Equivalente* – ISEE).[17]

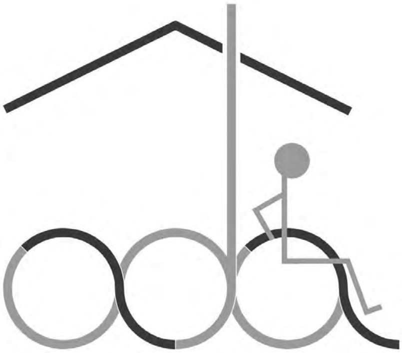

Figure 11 – ADA Project logo (by Antonio Laurìa).

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[17] The ISEE is an instrument adopted in Italy for assessing the financial status of families. It takes into account income, assets and property owned, as well as the characteristics of the family nucleus (number and type).

CHAPTER 4

Methodological Design

> Due to its very nature, the healthcare and rehabilitation process for people with severe disabilities is extremely complex. The definition of effective, reliable and consistent housing adaptations to increase autonomy at home is a tough challenge. The ADA Project's methodological design and the phases presented in this chapter attempt to address this challenge.

4.1 Introduction

To achieve its goals, the ADA Project applies a methodological concept inspired by the Performance-based Design approach defined by Gibson (1982: 4) as "the practice of thinking and working in terms of ends rather than means. It is concerned with what a building or building product is required to do, and not with prescribing how it is to be constructed."

This design comprises a *preparatory phase*, three *implementation phases*, and an *ex-post evaluation phase.*

The *preparatory phase* has two goals: to draft the project procedures and operating tools and create a common knowledge base through specific training activities for the members of work groups operating in the health districts. Training is essential, given the different backgrounds of the various members of the interdisciplinary work groups (physicians, social workers, architects, etc.) and the complexity of the challenges of the ADA Project.

The *implementation phases* have three main tasks: (1) a site survey to assess the functional limitations, social context and physical home environment of the disabled persons who participate in the project; (2) drafting of very personalised accessibility recommendations to define housing adaptations; (3) profile assessment of the disabled persons and of critical environment, family and social situations that hinder their autonomy at home, with the purpose of defining and assigning a grant for proceeding with interventions.

The *ex-post evaluation phase* analyses the ways in which a process is implemented and the results, both expected and unexpected, that it produces (Preiser & Vischer, 2005; Costa, 2014). The ex-post assessment takes on a special connotation in the case of housing adaptations (see Gitlin, 1998; Fänge & Iwarsson, 2007). As mentioned earlier, since this phase is still in progress, its results will be described in a forthcoming publication.

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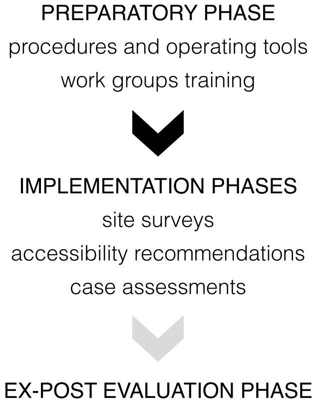

Figure 12 – ADA Project methodological design.

4.2 Preparatory Phase

The University of Florence Research Group's first action was to draft the procedures and operating tools for the ADA Project. These procedures and tools were tested during the ADA Project pilot phase undertaken by two Tuscany Regional health districts (Fiorentina Nord Ovest and Pratese). During this experimentation phase it was possible to identify several critical points that were solved/mitigated by patient, progressive refinement.

Before the beginning of activities, and with the purpose of obtaining procedures and results that were as homogeneous as possible and comparable throughout the entire regional territory, the members of the various work groups participated in a series of meetings regarding cultural, methodological, organisational and administrative aspects of the ADA Project. These training activities took place both in Florence (at the headquarters of the Tuscany Regional Government and of the Florence Accessibility Lab) and at the local level in the various health districts. They were conducted by the research group members with the cooperation of experts from other agencies involved in the project.

In particular, work groups architects attended 36 hours of project-specific training courses that touched upon several aspects of the ADA Project: (1) the context of the regional policies of which it is a part, (2) the people to whom it is addressed, (3) its various phases and operating tools, and (4) the administrative procedures regulating it.

Some topics addressed are not usually part of an architect's typical training: aspects of conduction of the site survey and entering the social context of persons with severe disabilities and of their families, which requires specific sociopsychological training; assistive and home automation technologies aspects; prosthetic assistance strategies (personalised medical aids and prosthetics).

Furthermore, work group architects underwent specific training in how to use the data production tool at the home of the disabled person (*ADA Assessment Model*; see Chapter 5). That also included a stage of field training, with two site surveys supervised by personnel from the University of Florence research group. This field training was necessary to familiarise with the specific complexities of the tool's contents and methods, which broach various fields of knowledge.

4.3 Implementation Phases

The ADA Project consists of three implementation phases:

- *Site surveys* for identifying the needs and wishes of the disabled person and of those who care and assist them in the home environment;
- *Accessibility recommendations*, for advising the disabled person and their relatives on organic set of possible interventions for adapting the home;
- *Case assessment* for deciding and assigning regional grants to the disabled eligible for adaptation of their homes.

4.3.1 Site Survey

The site survey at the homes of disabled persons participating in the ADA Project is the main opportunity for collecting data necessary both for drafting the accessibility recommendations and for case assessment. The site survey, however, develops deeper, more far-reaching meanings, expressing a sense of the regional institution's nearness to and attention for the severely disabled and their families, and where necessary is oriented to strengthening the care service. The site survey can also serve to identify additional measures of support for the person, as well as rehabilitation and/or training activities (for example, courses for learning to use or improving skills for new equipment and information technologies) directed at making the most of personal capacities in the home environment.

The site survey is based on two main guiding principles: personalisation of the analysis, and the interdisciplinary nature of the approach. It intends to produce data relevant to three assessment areas: (1) *Limitation to functional autonomy* of the disabled person, (2) *Assistance and social deficits*, and (3) *Accessibility issues* in the home environment.

The analysis of the disabled person's functional limitations, knowledge of their family, their social and healthcare services context, assessment of their dwelling's accessibility issues, their personal stories, etc. are taken into account with regard to the various home activities, and addressed by all members of the work group, each with their own expertise. In particular, the physician is responsible for acquiring information and data on the disabled person's *limitation to functional autonomy*; the social worker assesses *assistance and social deficits*; *accessibility issues*[1] – in the form of *architectural barriers* to be removed and *facilitators* to be added – are the task of the architect.

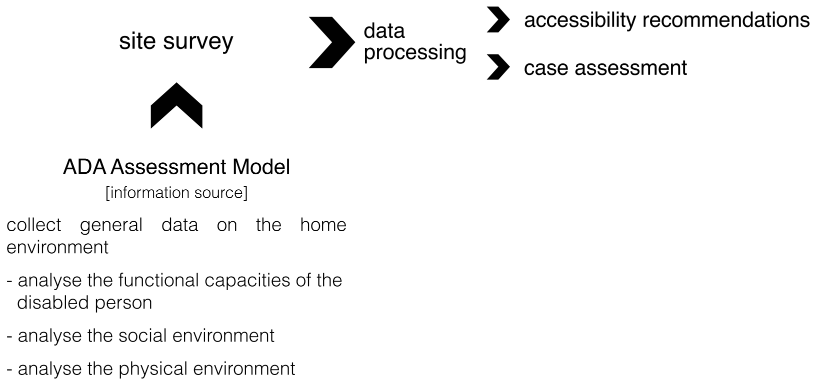

Figure 13 – Diagram of the data flow during and after the site survey.

In order to ensure a method as consistent as possible across the various health districts, the University of Florence Research Group, in addition to the training activities described above, established a specific procedure for conducting site surveys, from the preliminary stage to the completion. A summary of the procedure is given at the end of paragraph 5.2, in Table 6.

The survey begins by explaining to the disabled person and/or their family or professional caregiver the aims of the ADA Project, as well as how the survey is conducted.

This initial phase of the survey is always conducted by the work group's social and healthcare services personnel. This approach came from the desire to conduct the interview informally, and since the social and healthcare services operators already know the disabled person, they are best suited for the task.

> In the unlikely event of the disabled person being absent during the site survey, the direct knowledge of the applicant previously acquired by social and healthcare services members of the work group has proved to be fundamental and of great help to the architect for establishing a reliable overview of the dwelling's accessibility issues.

Subsequently, the core of the survey is addressed, using specific data sheets to gather information on the disabled person, their family and social environment, and the accessibility of their dwelling.

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[1] See § 2.3.

After the site survey, and only for disabled persons who are entitled to the regional grant for implementation of adaptations, a final quantitative assessment is made of their level of autonomy at home.

The design of the site survey data collection sheets takes into account the need to balance requirements with two opposite approaches. On the one hand the site survey has to produce data allowing construction of a *thick description*[2] of the disabled person's everyday home life. This is essential for reaching the level of understanding needed for drafting accessibility recommendations that offer solutions tailored to the specific requirements of the disabled person and their caregivers.[3] On the other hand, the need to ensure transparent distribution of regional grants foresees a complementary process that allows comparison of the cases through assessments that adopt criteria as standardised and structured as possible.

These two needs require very different data production strategies, so led to a long process to fine-tune investigative tools, oriented precisely to balance the resources required to produce both type of data.

An additional element taken into account was the need to produce data collection sheets immediately comprehensible for the members of all the work groups operating on regional territory. For example, the sheets for members of the social and healthcare services areas were designed to be as similar as possible to those they already use in their normal Multidisciplinary Assessment Unit (UVM/UVH) activities. This had the benefit of avoiding specific training which, for many of these members of the work groups, would have meant an unsustainable workload increase.[4]

Given the ADA Project's overall time and human resources, it was decided that site surveys should last 90 minutes on average.

The above-mentioned needs oriented the development of the *ADA Assessment Model* (AdAM) tool, which accompanied work groups throughout implementation phases, and which will be described in detail in Chapter 5. The purpose of the ADA Assessment Model is to produce all the data needed in the ADA Project's other two implementation phases: (1) the drafting of the accessibility recommendations, and (2) the case assessment to define and assign the regional grants.

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[2] The concept of *thick description*, developed by the anthropologist Clifford Geertz (1973), refers to that type of description that also provides elements on the context in which the phenomena described takes place, permitting an *outsider* to observe the depth and meanings of the process. In the case of the ADA Project this is what occurs in the complex relationship established between the disabled person, the aspects of their functional limitations and the physical and social environment in which they live.

[3] See Introduction and Chapter 1.

[4] As noted in § 4.2, specific training was instead contemplated for the architects of the work groups, since their tools include innovative features compared to the methods usually used to investigate accessibility issues.

4.3.2 The Accessibility Recommendations

The purpose of the Accessibility Recommendations (henceforth AR) is to provide the disabled persons participating in the ADA Project with a coordinated framework of personalised solutions useful for overcoming or decreasing accessibility issues in their homes.

What follows is an explanation of the process that allows the data gathered in the site survey to be converted into the information included in the AR.

Through the site survey, the work group reconstructs the profile of the disabled person (both from social and healthcare standpoints) and establishes an exhaustive picture of the accessibility issues that prevent or hinder activities being conducted at home. The *accessibility issues* are linked to the elementary activities included in the AdAM *Home Activities Checklist*.[5]

To define accessibility issues, the elementary activities which are difficult for the disabled person (e.g., "using the oven") are analysed in reference to their class of activity (e.g., "preparing meals") and to the specific *environmental unit*[6] in which they are carried out (e.g., "kitchen"). In some cases, elementary activities may be referred to the route connecting several environmental units or levels of the dwelling (e.g., elementary activity "moving between the various levels of the dwelling"), or to the dwelling as a whole (e.g., elementary activity "controlling and managing active safety systems").

> In order to clarify further the meaning of *class of activity* and of *elementary activity,* an example can be made regarding the class of activity defined "Taking care of personal hygiene." This is carried out through a series of elementary activities such as bathing and drying off completely (taking a bath or a shower) or partially (washing face, using the bidet, etc.), shaving, applying make-up, drying hair, etc.

An organic set of accessibility issues identifies a *challenge*[7] to address through the AR. For example, for a person in a wheelchair, the challenge "Difficulty in accessing the path to the dwelling" could indicate the following accessibility issues: a too-narrow doorway to the apartment building, a door too heavy to use, a door with an inadequate handle, a height change in the floor precisely where the door is situated, other height changes on the floor immediately beyond the door, etc.

This inductive process aims to build an overview of the accessibility issues in relation to the various classes of activities, with two strategic purposes:

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[5] See Section S6.3, § 5.2.

[6] Italian Standard UNI 10838:1999 defines an "environmental unit" as a grouping of spatially and temporally compatible user activities determined by the building's intended use. These environmental units include bedroom, living room, kitchen, etc. To avoid excessively technical language, the accessibility recommendations call environmental units "rooms".

[7] See "Accessibility Recommendations Structure and Content" in this paragraph.

1. Helping the work group architect to draft the AR and outline a detailed analysis of the *challenges* to address/overcome;
2. Helping the disabled person (and/or their caregiver/s) to understand the *challenges* and relate them to their location in the dwelling.

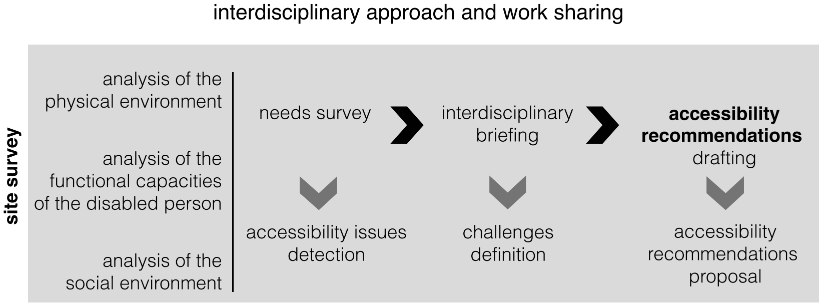

Figure 14 – From site surveys to accessibility recommendations

As already explained, the identification of accessibility issues is not based on current accessibility regulations and must take into account only obstacles the disabled person in question encounters when undertaking activities at home.[8] Conversely, personalised *solutions* included in the AR must comply with those regulations.

These solutions are related to three macro intervention areas:

- *Building works* (for example, construction of ramps to navigate height changes; widening of doorways; demolition and reconstruction of walls; conversion or adaptation of toilets and bathrooms, etc.).
- *Furniture and equipment* (for example, kitchen furniture and appliances, handrails, fittings and accessories for toilets and bathrooms, etc.).
- *Assistive and home automation technologies* (for example, mobile safety devices; automation systems for doors, windows and lighting, etc.) (see Mann, 2005; Morini & Scotti, 2005; Anson, 2018).

> Installation of assistive and home automation technologies can be essential for improving the living conditions of the disabled person (and/or caregiver/s) when neither building nor furniture and equipment interventions are considered efficient options for increasing the degree of autonomy or are worth the scale of investment considering the possible advantages. When the nature of the accessibility issues means assistive and home automation technologies are not an efficient option either, the AR highlight this limitation. Verification that reasonably applicable solutions are not sufficient to improve the accessibility and the safety of buildings (including in an emergency) may mean that the transfer of the family to another dwelling may be suggested when possible.

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[8] See Data Sheet S6 in Chap. 5.

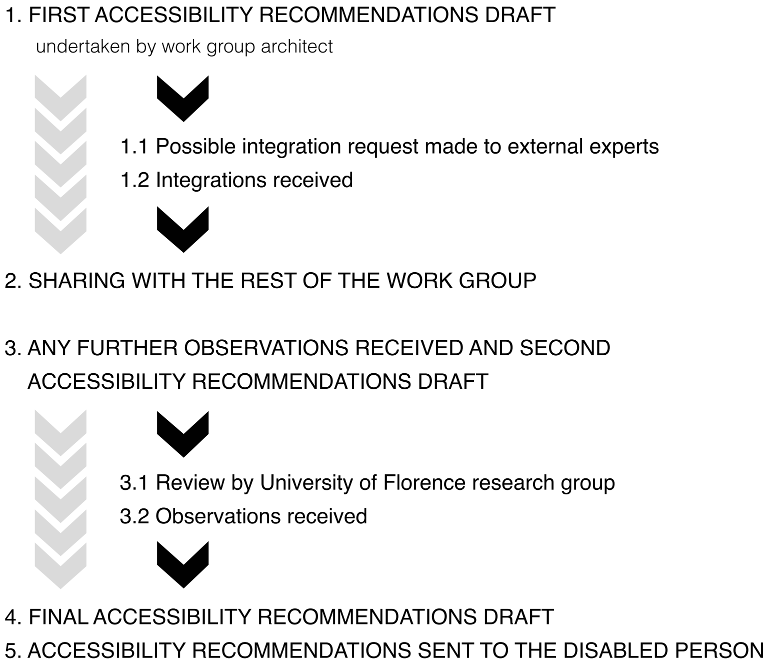

Figure 15 – Flow-chart of accessibility recommendations drafting procedure.

When drafting the AR, the work group architect refers to regulations, specialised texts, technical handbooks (see, *inter alia*, Lockhart, 1981, Goldsmith, 1997; Preiser & Smith, 2010), guidelines, international standards (such as ISO 2011) and online documentation from companies engaged in the field of accessibility and assistive and home automation technologies. An additional useful source of information is the list of *challenges-solutions* progressively developed by the ADA Project.[9] The list offers strategic opportunities since its aim is to expand the knowledge base supporting those who draft the AR when defining the most appropriate solutions. In general, its goal is to increase "project system intelligence" as well as standardise results. The solutions proposed in the AR, in particular those derived from specialised texts and handbooks, always consider market availability of the recommended products, systems, innovative technologies, furnishings, equipment, etc.

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[9] The list of challenges-solutions collected over time through the project's various accessibility recommendations represents a main support for the creation and updating of a database design solution for housing adaptation.

Since the implementation phases of the ADA Project involve a large number of professionals, the procedural aspects assume crucial importance in ensuring the quality and uniformity of AR contents.

As shown in Fig. 15, the preliminary processing of data and information gathered during the site survey is carried out by the work group architect, who presents a first "draft" of the AR, and when necessary this includes input from the "external experts".[10] This document is then shared with the other members of the work group, who can propose observations or modifications, which the architect includes in a second draft of the AR. If necessary, the University of Florence research group[11] may proceed to revise the draft. This process leads to the final version of the accessibility recommendations drawn up by the architect, who sends them to the Regional Accessibility Centre. Finally, the AR are sent to the disabled person by its health district.

The AR have a mid-to-long-term validity: in other words, they are a document that can guide adaptations for a period that goes well beyond that of the duration of the ADA Project.

Accessibility Recommendations Structure and Content

The Accessibility Recommendations are a document comprising both text and images (photographs and drawings) that contains proposed design solutions. Of the latter, any that are a *priority* for the disabled person are highlighted, whether they refer to needs expressed by the applicant or by their caregiver/s, or identified by a member of the work group. Priority solutions are those fundamental for increasing the disabled person's level of home autonomy and facilitating caregiver assistance.

To ensure adequate uniformity for all AR drafted by the various architects who operated on regional territory, a standard *Accessibility Recommendations Model* was designed.[12]

> The *Accessibility Recommendations Model* was developed considering the objectives of the ADA Project and applying the principle of seeking uniformity in three different areas: (1) content organisation (document structure); (2) the way of presenting contents (appropriate language easily understood by the various readers);[13] (3) typology of proposed solutions in relation to the needs of the disabled person in their home environment.

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[10] Health district social and healthcare services personnel and "A. Faedo" Institute of Science and Technology of Information (ISTI) engineers and experts in technologies from Pisa's National Research Council (CNR).

[11] See § 3.1.4.

[12] The *Accessibility Recommendations Model* was developed by the University of Florence research group and was shared with the other members of the work groups who took part in the ADA Project pilot phase, to gather observations and suggestions for its improvement.

[13] It is important to consider that the accessibility recommendations are not only for disabled persons participating in the project, but also for the various professionals

In order to achieve its objectives, the *Accessibility Recommendations Model* was progressively simplified during the ADA Project pilot phase until a final version was defined.

The Accessibility Recommendations Model comprises three sections:

1. *Preliminary section*, containing general information;
2. *Central section*, containing the *challenges* identified during the site survey and the description of the *solutions* proposed for overcoming them:
3. *Conclusion*, containing useful indications to guide the disabled persons requesting the grant in the stages that follow the reception of the accessibility recommendations.

The preliminary section contains an overview of the AR and indications for making them easier to read. It includes (1) the recipient's name, the date of the site survey and the names of the participating members of the work group; (2) an overview of the central section of the AR; (3) a notice advising on the purely indicative value of the AR;[14] (4) the names of the members of the drafting work group.

Table 1 – Summary of the contents of the preliminary section of the accessibility recommendations.

Accessibility Recommendations PRELIMINARY SECTION: structure and contents	
General information	*Specific information*
– Beneficiary – Date and place of site survey – Participants in the site survey – Authors of the AR – Date and place of the AR – AR alphanumeric identification code	Overview illustrating the structure of the AR central section of the AR Notice advising the AR has a purely indicative value

The overview lists the *design data sheets* of the central section of the AR, each identified by a letter (e.g.: Data sheet A, Data sheet B, etc.). Each data sheet refers to an *environmental unit*, including horizontal and vertical connecting paths (e.g.: bathroom; bedroom; living room; kitchen; balcony; stairs, corridor, internal staircase, etc.). For each data sheet (and therefore for every environmental unit), a summary of the *challenges* is presented, in relation to the activities that the person carries out or would like to carry out in the

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involved in defining and implementing adaptations: architects, plant designers, installation personnel, artisans, building material and component vendors, etc.

[14] The notice also states that it may be necessary to engage building industry professionals (architects, structural engineers, building services engineers, etc.) to define detailed solutions to be adopted and to obtain any necessary administrative permits in compliance with applicable regulations for building modification.

dwelling (e.g., in the case of the data sheet regarding the environmental unit "Bathroom": "Difficulty in using the toilet safely"). The overview highlights the data sheets containing *solutions* that would ensure the disabled person tangible improvement in autonomy for performing activities at home. These solutions are proposed in order of priority. Whenever the disabled person is unable to carry out all the proposed interventions simultaneously, at their own discretion they can apply a suggested order of priority.

The central section of the AR is the core of the document. Every design data sheet is organised in three sections: (1) *Challenges*; (2) *Solutions*; (3) *Images*.

The *Challenges* section contains a brief account of the accessibility issues noted during the site survey in relation to the activities conducted at home by the disabled person and their caregiver/s.

The *Solutions* section describes in depth the adaptations proposed with the purpose of overcoming the challenges identified. Whenever possible, for each challenge, a set of alternative solutions is proposed, to provide more choices and allow better personalisation of solutions, both for the economically commitment and for the actual correspondence to the needs and expectations of the disabled person.

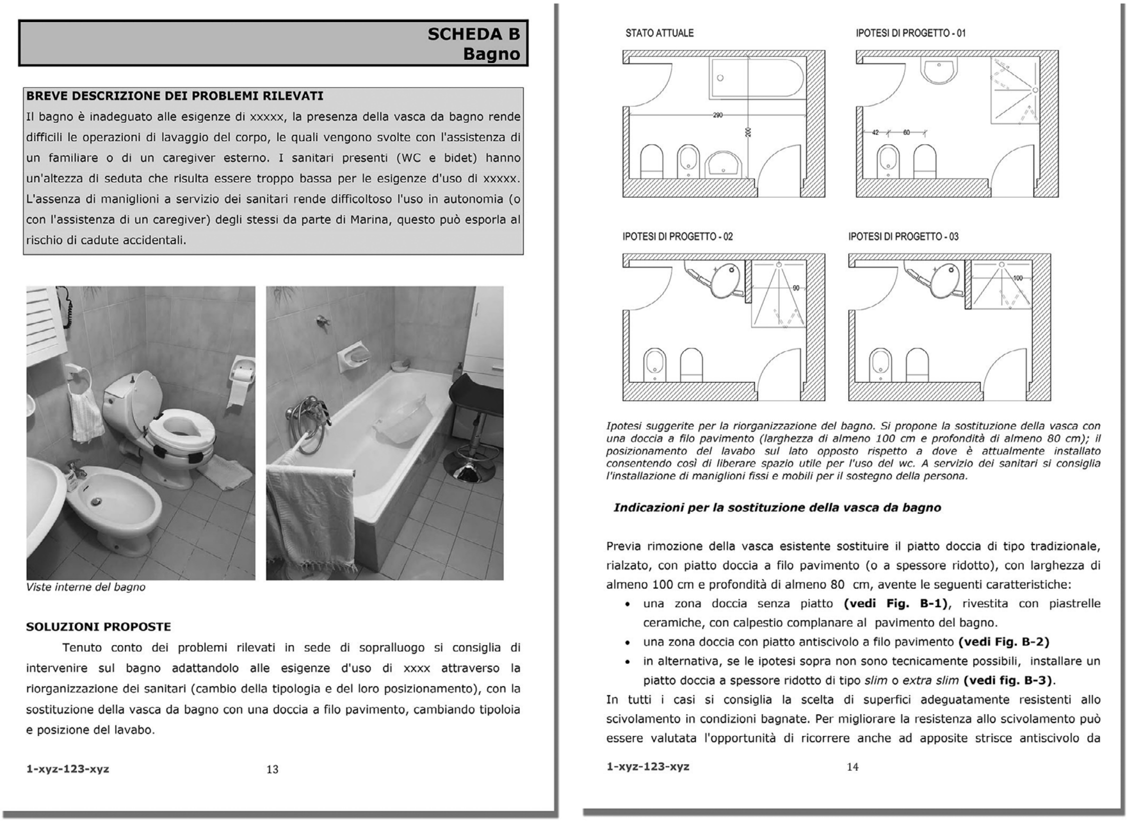
Table 2 – Contents of the central section of the accessibility recommendations.

Accessibility Recommendations CENTRAL SECTION: structure of design data sheets		
SECTION 1 *Challenges*	*SECTION 2* *Solutions*	*SECTION 3* *Images*
Short description of challenge/s on the basis of accessibility issues noted during the site survey	In-depth description of the adaptations considered appropriate for overcoming challenge/s mentioned in Section 1	A series of photographs and drawings useful for illustrating the solutions proposed in Section 2

A detailed description of the products proposed is always provided in the AR, to guide the disabled person and their caregivers in seeking the most appropriate items for their needs. Since the AR are a document produced by a public administration, to avoid unfair advantages they cannot contain any reference to the trade names of specific products.

The *Images* section consists of a collection of photographs and drawings (e.g., plans, sections, sketches, photomontages, etc.) that illustrate the proposed solutions. The iconographic material aims to accompany and illustrate the text and facilitate its comprehension. When possible, the choice of images depicting products, components, equipment and furnishings focuses on *universal* products, without suggesting products specifically for the disabled.

The *Conclusion* of the AR contains additional information useful for the adaptations. In particular: (1) hints on how to benefit from tax incentives for some types of adaptations and purchases; (2) description of the subsequent obligations to be fulfilled in case of requesting a grant.



SCHEDA B
Bagno

BREVE DESCRIZIONE DEI PROBLEMI RILEVATI

Il bagno è inadeguato alle esigenze di xxxxx, la presenza della vasca da bagno rende difficili le operazioni di lavaggio del corpo, le quali vengono svolte con l'assistenza di un familiare o di un caregiver esterno. I sanitari presenti (WC e bidet) hanno un'altezza di seduta che risulta essere troppo bassa per le esigenze d'uso di xxxxx. L'assenza di maniglioni a servizio dei sanitari rende difficoltoso l'uso in autonomia (o con l'assistenza di un caregiver) degli stessi da parte di Marina, questo può esporla al rischio di cadute accidentali.

Viste interne del bagno

SOLUZIONI PROPOSTE

Tenuto conto dei problemi rilevati in sede di sopralluogo si consiglia di intervenire sul bagno adattandolo alle esigenze d'uso di xxxx attraverso la riorganizzazione dei sanitari (cambio della tipologia e del loro posizionamento), con la sostituzione della vasca da bagno con una doccia a filo pavimento, cambiando tipoloia e posizione del lavabo.

1-xyz-123-xyz 13

Ipotesi suggerite per la riorganizzazione del bagno. Si propone la sostituzione della vasca con una doccia a filo pavimento (larghezza di almeno 100 cm e profondità di almeno 80 cm); il posizionamento del lavabo sul lato opposto rispetto a dove è attualmente installato consentendo così di liberare spazio utile per l'uso del wc. A servizio dei sanitari si consiglia l'installazione di maniglioni fissi e mobili per il sostegno della persona.

Indicazioni per la sostituzione della vasca da bagno

Previa rimozione della vasca esistente sostituire il piatto doccia di tipo tradizionale, rialzato, con piatto doccia a filo pavimento (o a spessore ridotto), con larghezza di almeno 100 cm e profondità di almeno 80 cm, avente le seguenti caratteristiche:

- una zona doccia senza piatto **(vedi Fig. B-1)**, rivestita con piastrelle ceramiche, con calpestio complanare al pavimento del bagno.
- una zona doccia con piatto antiscivolo a filo pavimento **(vedi Fig. B-2)**
- in alternativa, se le ipotesi sopra non sono tecnicamente possibili, installare un piatto doccia a spessore ridotto di tipo *slim* o *extra slim* **(vedi fig. B-3)**.

In tutti i casi si consiglia la scelta di superfici adeguatamente resistenti allo scivolamento in condizioni bagnate. Per migliorare la resistenza allo scivolamento può essere valutata l'opportunità di ricorrere anche ad apposite strisce antiscivolo da

1-xyz-123-xyz 14

Figure 16 – Accessibility recommendations: excerpt from a design data sheet for bathroom adaptation.

Table 3 – Contents of the Accessibility Recommendations Conclusions.

Accessibility Recommendations CONCLUSION: general information	
For all participants	*For participants applying for a Grant*
Information regarding possible tax incentives for carrying out housing adaptations	Formalities to be carried out after receiving the accessibility recommendations Indication of categories of expenses covered or otherwise by the grant Address for receiving information

So far, 336 AR have been drafted and sent to ADA Project participants. Of these, 275 regarded the homes of persons entitled to a regional grant.

4.3.3 Case Assessment

In addition to the accessibility recommendations, the ADA Project may also envisage assignment of a grant for housing adaptations, and in some cases may cover all costs. The grant, as already stated, is paid to participants whose standard ordinary ISEE[15] for the family nucleus is under an annual 36,000 euros.

To ensure correct regional grant distribution within each health district, it was necessary to design an assessment system that was able to integrate not only environmental but also social and health aspects.

The assessment begins during the site survey at the home of the disabled person but is mainly pursued once the site survey has been completed. It is based on all data produced during the site survey and it is performed using the three AdAM *Assessment Data Sheets,* each referring to one of the three different assessment areas:

1. *Limitation of functional autonomy*, which considers the state of health and "intrinsic" conditions of the disabled person (age, physical condition, the possible progressive nature of the functional limitation, etc.);
2. *Care and social deficits*, which take into consideration the factors of the *social* environment that obstruct the disabled person performing domestic activities;
3. *Accessibility issues*, which consider the factors of the *physical* environment which prevent or impede performance of activities at home by the disabled person and caregiver assistance and care activities.

> The assessment process begins during the site survey but, as we will see, is completed only after all health district participants have been assessed. Before that moment, all assessments are considered as "provisional" and to be confirmed collectively by the work group. This is especially true for assessment of accessibility issues. Indeed, scores initially assigned by the architects are always discussed within the work group so as to involve several skill sets in the assessment process. The analysis of accessibility issues which takes place during drafting of the accessibility recommendations is also useful for assessment purposes. In point of fact, this analysis may also be useful for establishing a clear picture of the level of autonomy at home of the disabled person and of the workload of the caregiver/s in the home being assessed.

Once all the disabled applicants have been assessed, the scores from the three Assessment Data Sheets are used to calculate the level of *Autonomy at Home Limitation* for each of the participants.

Subsequently, after receiving housing adaptation proposals from all the disabled persons applying for a regional grant, the work group prepares the *Autonomy at Home Limitation Ranking* and decides grants.

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[15] See note 17, at the end of Chap. 3.

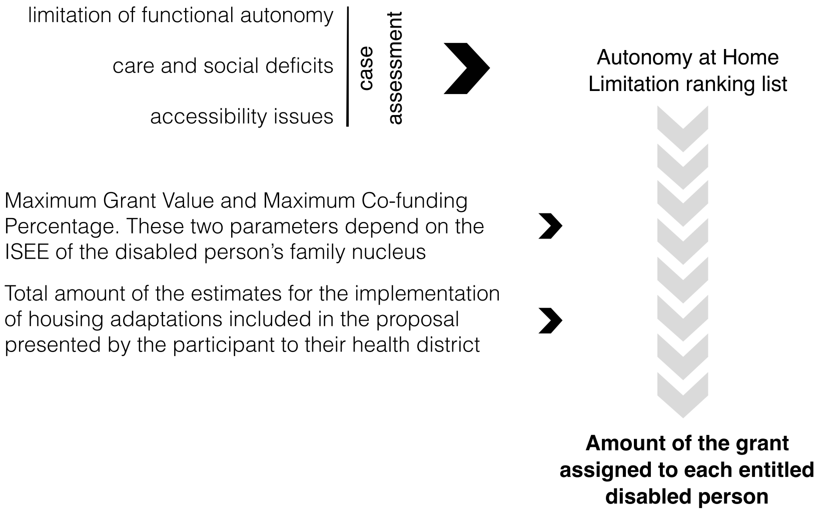

Figure 17– Procedure for grant assignment.

Criteria for grant assignment

As mentioned above, the only requirement for access to the grant offered by Tuscany Regional Government is that the ISEE for the applicant's family nucleus is not in excess of 36,000 euros.

The ISEE value is important for defining two of the parameters that influence the amount of the grant:

1) *Maximum Grant Value*, in other words the maximum amount the Regional Government pays to a beneficiary;
2) *Maximum Co-funding Percentage*, in other words the maximum proportion of the total costs incurred by a beneficiary for the housing adaptation that may be reimbursed by the Regional Government.

As shown in Table 4, the Maximum Grant Values are based on eight ISEE brackets, ranging from 1,800 to 4,600 euros.

The Maximum Co-funding Percentages increase as the ISEE calculated decreases, based on the same eight brackets. As established by Tuscany Regional Government, the co-funding percentages range from 50% to 100%, with full funding for all beneficiaries with a family nucleus ISEE lower than 6,000 euros.[16]

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[16] The nature of these parameters and of the ISEE brackets to which they refer are the result of a consultation between the University of Florence Research Group and the General Directorate of Citizen Rights and Social Cohesion – Social and Health Integration Policies Sector (*Direzione Generale Diritti di Cittadinanza e Coesione*

Table 4 – The two parameters for assignment of the grants, both linked to eight ISEE brackets: Maximum Grant Value and Maximum Co-funding Percentage.

ISEE	Maximum Grant Value	Maximum Co-funding Percentage
Up to 5,999 €	4,600 €	100%
From 6,000 to 8,999 €	4,200 €	80%
From 9,000 to 11,999 €	3,800 €	75%
From 12,000 to 14,999 €	3,400 €	70%
From 15,000 to 17,999 €	3,000 €	65%
From 18,000 to 20,999 €	2,600 €	60%
From 21,000 to 23,999 €	2,200 €	55%
From 24,000 to 36,000 €	1,800 €	50%

For the disabled entitled to regional funds these parameters are a necessary point of reference for calculating the amount estimated by the intervention proposal for which they are requesting a grant. In this way they are aware that there is a ceiling on the amount they may receive as co-funding for their housing adaptations and in turn this is defined by their ISEE.

> In any case, given the limited amount of the grant contemplated – and especially considering the high cost of the most common adaptations – it was important not to generate excessive expectations in the disabled persons with regard to the regional grant available. For this reason, ADA Project communication strategies highlighted that in most cases the disabled persons entitled should consider the regional grant as a support for the implementation of *part* of the interventions proposed in their accessibility recommendations or, in some cases, a support for the implementation of just one.[17]

Thus, the actual amount of the grant assigned to each entitled disabled person is defined by a combination of three factors:

- Score on the *Autonomy at Home Limitation* ranking list defined by the ADA Assessment Model described in Chapter 5;
- *Maximum Grant Value* and *Maximum Co-funding Percentage*. These two parameters depend on the ISEE of the disabled person's family nucleus;
- Total amount of the estimates for the implementation of one or more housing adaptation action of those suggested in the accessibility recommendations and included in the proposal presented by the participant to their health district.

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sociale – Settore Politiche per l'integrazione socio-sanitaria) of Tuscany Regional Government, who had the final decision on this and other matters.

[17] In the call for applications it was however envisaged that grants may exceed established limits. For example, in the event that some participants request less than their upper limit, there would be a residual availability of funding for other participants.

At the conclusion of the assessment and distribution of resources process each health district publishes the amount granted to each participant. From that moment on the beneficiaries of the grants have four months[18] to implement housing adaptations. They then have to produce the appropriate receipts to obtain the assigned reimbursement.

4.4 Ex-post Evaluation Phase

The ex-post evaluation phase can begin only after the adaptation interventions have been completed and after their effects on the disabled person and/or their caregiver/s can be ascertained. For these reasons, at the time of publication of this book this phase of the ADA Project is still in progress.

The ex-post evaluation has two main aims. Firstly, to produce detailed information and wisdom from the perspective of the disabled and their caregivers with regard to the implementation phases of the project in which they were more directly involved. The second goal is to assess the impact of the implemented housing adaptations on the most important aspects addressed by the ADA Project: personal autonomy, accessibility, and more generally, the well-being and quality of life of the disabled persons and their caregivers. In this case the evaluation must verify whether the adaptations bettered the housing conditions of the disabled person and those of their caregivers.

Regarding the first goal, it is useful to point out some of the main research questions under investigation:

- *Project* *communication*. What processes structured the access to information about the ADA Project? What dynamics of the disabled person's social network played a role in guiding their participation? What aspects of Project communication motivated their participation?
- *Call for applications*. Which elements in the call for applications were most difficult to understand? Which, instead, were the most clear and effective?
- *Site survey*. How was the survey experienced by the disabled persons and their caregivers? Which were the most difficult elements in the relationship with the work group? Which, instead, were the aspects that most favoured the establishment of a relationship of trust between the disabled person (and/or the caregiver/s) and the work group and therefore were most helpful in carrying out an in-depth site survey?
- *Accessibility Recommendations*. How were the AR received? What were the major difficulties in their interpretation and understanding? Which, instead, were their strong points? Was communication clear and effective for the steps needed to implement the solutions suggested in the AR? Which factors external to the ADA Project played a bigger role in

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[18] This time frame may be extended following a duly justified request.

deciding the choices of the disabled persons and their caregivers regarding the interventions to be carried out?

- *Case assessment and grant assignment.* Which were the major problems encountered during this phase? Did the mechanism requiring advance payment by the disabled person and subsequent reimbursement by the health district work properly? Which were the main factors that led some disabled persons not to present applications for grants?

The second objective of the ex-post evaluation is to assess the impact of adaptation actions suggested by the ADA Project. This type of evaluation must take into account several aspects typical of the project and the process applied to for proposing how to achieve strategic objectives.

Indeed, through the accessibility recommendations, the ADA Project suggests a series of interventions, each of which is shaped by a set of intentions related both to the project's main goals and the specific conditions of the disabled person it addresses. The process that goes from these suggestions to their implementation and use by disabled people, does however involve a series of stages and range of players not directly controlled by the ADA Project itself. This means that an evaluation of the impact of the project cannot be limited to studying whether suggestions were "correct" or controlling if and to what extent the expected outcomes of those suggestions have been achieved by the completed intervention. On the other hand, it also has to analyse the process put in place between (1) the delivery of the accessibility recommendations and the (possible) assignment of the grants, and (2) the final implementation and use of those adaptations.

The design of such an ex-post evaluation has to consider the extensive personalisation that informs the design, the tools and the implementation of the ADA Project. This means, for example, that simply assessing if the interventions put in place after the ADA Project comply with current regulations on accessibility does not guarantee that those same interventions can actually reach their expected personalized outcomes.

To respond to these challenges, the ex-post evaluation of ADA Project outcomes requires a two-stage strategy. First, it is necessary to adopt a qualitative and heuristic approach making it possible to identify the most important processes and aspects affecting the impact of the interventions, both during the project's implementation phases and those that followed, up to completion and their use by the disabled person. This stage is conducted on a relatively small sample of cases, using in-depth interviews and unstructured observation of the homes after the interventions.[19]

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[19] As Patton (1987:24-26) highlights, qualitative research tools are particularly useful for evaluating what he calls "individualised outcomes", such as the highly personalized interventions proposed by the ADA Project. This way of addressing these kind of research questions is typical of the more constructivist approaches to *Post-*

Then, in a second stage, the evaluation will adopt tools to test the hypothesis developed in the first evaluation stage and build distributions that give a quantitative outline of the project's effects. The evaluation strategy of these aspects will only be addressed after completion of the first stage of the ex-post evaluation, which, as already mentioned, is currently in progress.

Occupancy Evaluation (POE), a research practice that deals precisely with the ex-post evaluation of the effects of the interventions on spaces once they are inhabited by their final users. For an analysis of the approaches to POE, see Costa (2014).

CHAPTER 5

The ADA Assessment Model

The implementation phases described in the previous chapter are driven by a multidisciplinary set of tools included in the ADA Assessment Model. From a scientific and methodological perspective, this tool is the main achievement of the ADA Project. Its aim is to make a thorough assessment of the interaction between a disabled person and their own physical, care and social home environment. The model is the key source of information both for the accessibility recommendations and for grant assignment to the disabled persons who are entitled to them.

5.1 Introduction

The *ADA Assessment Model* (henceforth, AdAM) is the work tool summing up the principles underlying the ADA project. It is based on an interdisciplinary approach focused on three inter-related components: (1) the persons with their functional capacities; (2) the care and social network they can count on; (3) the accessibility of their own home environment. These components are analysed in relation to the activities that the person, including with the support of a caregiver, carries out at home. The analysis of the activities at home is therefore the core of the AdAM (Fig. 18).

> In this respect it is worth recalling the assessment of personal abilities proposed by the *Capability Approach*, which examines three main elements: (1) the *person*, (2) the *activity*, and (3) the *environment*.[1] The *person* represents the fulcrum of the model; it is the figure who would like to carry out a certain activity in a certain environment. This person has certain abilities (for example: physical strength, visual acuity, etc.) that can change at any time. If the person does not have the necessary ability to carry out the activity in a certain way, they might still be able enough to undertake the activity in a different way, under certain conditions. *Activity* is made up of a series of individual actions and requires certain abilities to be carried out satisfactorily. The *environment* is the context in which the person carries out the activity.
> In ICF language "activity" (the execution of a task or action by a person in their living environment) and "participation" (the involvement in a life situation) are described by two qualifiers: (1) *performance*, namely what a person does in their actual environment, and (2) *capacity*, namely what a person does

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[1] On *Capability Approach* see: Sen (1987) and Nussbaum (2011). On *Capability Approach* applied to disability and accessibility see, respectively, Biggeri & Bellanca (2011) and Tyler (2011).

Antonio Laurìa, Beatrice Benesperi, Paolo Costa, Fabio Valli, *Designing Autonomy at Home. The ADA Project. An Interdisciplinary Strategy for Adaptation of the Homes of Disabled Persons*, ISBN (online PDF) 978-88-6453-898-3,

> in a situation in which the effect of the context is absent or made irrelevant. The combination of *performance and capacity* enables an understanding of the influence of the environment on a person; the difference between *performance* and *capacity* provides guidance for what kind of intervention may be undertaken on the environment for the purpose of improving the *performance* of individuals. Furthermore, according to the ICF approach, "environmental factors" – namely the features of the environment (physical, social and attitudinal) in which persons live – can prove to be either *barriers* or *facilitators* in their lives. Barriers reduce the *performances* of the person in carrying out an activity; facilitators increase them (WHO, 2001; 2013). Theoretical approaches and instruments targeting Person-Environment-Activity (P-E-A) transactions have also been developed in the field of occupational therapy (see Law *et al.*, 1996; Fänge & Iwarsson, 2005).

The AdAM has two main goals. First, it allows production of structured information that aims to define highly personalised housing adaptations, then suggested in the accessibility recommendations. Second, it allows detailed assessments of the person's autonomy in the care, social and physical context where they live. These assessments aim to define and assign – through the case assessment phase – the regional grants for the implementation of the adaptations undertaken by participants in the ADA Project.

It can thus be said that the AdAM is a housing needs assessment and data production tool.

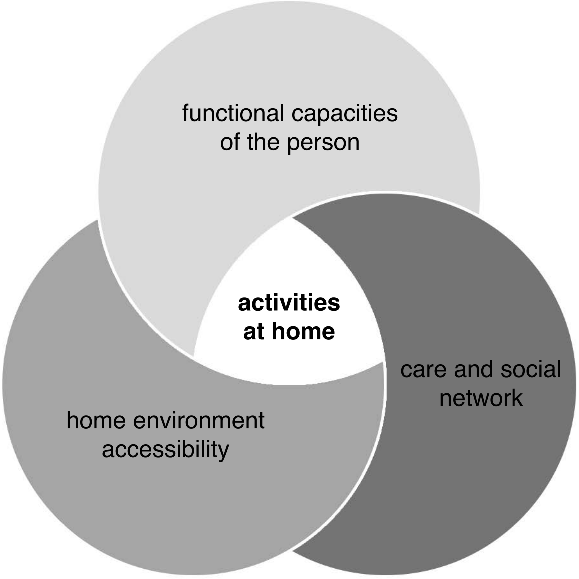

Figure 18 – The three inter-related components of the ADA Assessment Model are analysed in relation to activities at home.

ADA Assessment Model

SITE SURVEY DATA SHEETS (S)

S1 General Site Survey Data
S2 Disabled Person's General Data
S3 Analysis of the Disabled Person's Level of Autonomy
S4 Analysis of the Social Environment
S5 Other Notes on the Disabled Person's Social and Health Profile
S6 Analysis of the Physical Environment
  S6.1 General Home Information
  S6.2 Other Observations on the Physical Environment
  S6.3 Home Activities Checklist
  S6.4 Accessibility Issues Survey

ASSESSMENT DATA SHEETS (A)

A1 Limitation of Functional Autonomy Assessment
A2 Care and Social Deficits Assessment
A3 Accessibility Issues Assessment

A4 Autonomy at Home Limitation Score

Figure 19 – The structure of the ADA Assessment Model, with its two parts: Site Survey Data Sheets (S1-S6) and Assessment Data Sheets (A1-A4).

The AdAM also collects data not strictly related to housing adaptation, but to the disabled person's other needs. These data may be useful to Tuscany Regional Government for further programmes/services for the disabled.

The AdAM is composed of ten data sheets: six Site Survey Data Sheets and four Assessment Data Sheets.[2] The former are completed for all ADA Project participants; the latter are to be filled out only for those entitled to the grant who have requested it.

The description of the AdAM structure, which is seen in a summarised form in Fig. 19, helps understand the aims of its various sections and their use. The AdAM is reproduced in its entirety in the Annexe to this book.

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[2] For a description of the Site Survey Data Sheets, see § 5.2; for a description of the Assessment Data Sheets, see § 5.3.

5.2 Site Survey Data Sheets

The first part of the AdAM consists of six data sheets and is used to obtain information on the health conditions and functional limitations of the disabled person, the characteristics of their family and social environment, and the accessibility of their dwelling.

Data Sheet S1: General Site Survey Data

Data Sheet S1 contains the following information: (1) the disabled person's details; (2) place, date and time of the site survey; (3) other people present during the site survey (specifying their relationship to the disabled person); (4) members of the work group, and their respective roles.

Data Sheet S2: Disabled Person's General Data

Data Sheet S2 contains information on the disabled person. Some of this contributes to defining with greater precision the type of disability the participant presents: diagnosis, description of aids or other devices they use and – when appropriate – the progressive nature of the functional limitation. This information can be particularly useful in drafting the accessibility recommendations.

> As already noted, having information on the possible evolution of the disabled person's functional limitation is essential for identifying the most appropriate housing adaptations. For example, a diagnosis that envisages a progressive reduction of motor capacities may advise against design solutions that make a certain activity easier, perhaps with the use of automatic controls, and instead favour solutions requiring greater physical effort, in order to keep the remaining functional capacities as active as possible, thus slowing down deterioration.[3]

The other information included in this data sheet refers (when appropriate) to the level of education of the disabled person and their professional status, also mentioning any working activities carried out at home; and, lastly, to their inclusion in specific socio-therapeutic and rehabilitation programmes.

Data Sheet S3: Analysis of the Disabled Person's Level of Autonomy

Data Sheet S3 adopts the *Barthel Index*,[4] a tool that defines the level of autonomy with which the disabled person is capable of carrying out ten activities related to ADLs and mobility (Mahoney & Barthel, 1965). The *Barthel*

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[3] See § 1.4.2.

[4] *Ibidem.*

Index is well known in literature and well consolidated in the healthcare field (see Collin *et al.*, 1988). It has been used for a long time in the assessment of autonomy (in particular in elderly post-stroke patients). It is also already in use in Tuscany and therefore known to medical personnel participating in the work groups.

The decision to include this tool in the AdAM was motivated by the desire to examine the functional situation of the disabled person in a structured manner.

The AdAM adopted the *Modified Barthel Index* (see Shah, Vaclay & Cooper, 1989), which proposes a more analytical system of assessment than its original 1965 version. For every activity there are five description options, which correspond to five degrees of increasing autonomy, in turn associated to increasing scores; the sum of the ten scores creates an index that in the case of maximum autonomy totals 100 points (instead of the 20 points of the original version).

> Depending on the type of activity the assigned scores range from 0 to 5, 0 to 10, or 0 to 15 points.
> This version is also that adopted in many cases by Tuscany Regional Government. In the AdAM a few slight lexical modifications were introduced, in order to make the translation from the English clearer and more specific to disability. For example, the word "patient", which appeared several times in the original version, was eliminated.

In the Data Sheet S3 the autonomy of the disabled person is analysed in a so-called *standard environment*, in other words focusing on the capacities of the disabled person and not considering the specific features of the physical environment in which the person actually lives.[5] In this part of the AdAM *only* the person's functional capacities in relation to their state of health are assessed, whereas those linked to their relationship with the environment are explored (and assessed) in other parts of the AdAM.[6]

The completion of this analytical tool is relatively simple and can be carried out in a few minutes, especially when the state of health of the disabled person is already known by the social and health services.

This data sheet makes it possible to establish a sufficiently clear picture of the disabled person's functional limitations (including dependence on mobility aids), and this knowledge is important in various ways. First of all, it allows identification of so-called *compatible activities*, in other words those activities the disabled person can carry out with their actual functional

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[5] In terms of the ICF theoretical framework, it is the *capacity* of the person and not their *performance* in the environment where they actually live that is examined (WHO, 2001: 19-20 and 208-210). See also § 5.1.

[6] See Data Sheet S6, Sections S6.3 and S6.4, in this paragraph; and Data Sheet A3, in § 5.3.

condition, health, age and psychological development.[7] Indeed, it makes no sense to look for accessibility issues regarding activities the disabled person is unable to perform. Therefore, and also thanks to the *Modified Barthel Index*, the work group can restrict the survey field to examining the accessibility issues that will be effectively and subsequently faced. Secondly, having in-depth knowledge of the disabled person's functional conditions allows greater precision in the choice of design solutions to be suggested in the accessibility recommendations. Finally, as can be seen below, the final autonomy score produced in this data sheet also plays a role in assessment for assignment of regional grants.

Data Sheet S4: Analysis of the Social Environment

The purpose of this data sheet is to allow the work group's social worker to collect more information about the disabled person's human relationships and their participation in society, to assess if care needs related to their functional condition, as well as their social-relational needs (see WHO, 2001; UN, 2006), are being met. This information helps the work group to obtain an in-depth picture of the disabled person's social environment, with an awareness of the close relationship that exists between social and care environment and autonomy at home.[8]

This kind of analysis would require examination of a wide variety of aspects but when designing the tool an attempt was made to select only the aspects more strictly related to ADA Project goals. In other words, an effort was made to balance the need for obtaining as much information as possible about the disabled person's social environment with that of not making the site survey too "heavy".

> In order to achieve this balance, this part of the AdAM was devised in two stages. The first included all the questions seen as connected in some way to the ADA Project; later, working with several social workers, a selection was made, eliminating parts that were less relevant, as well as those that might embarrass the disabled person or their relatives.[9] Addressing issues whose meaning or links to project aims are not so clear could generate a defensive attitude in the person interviewed and undermine the relationship of trust with the work group, which is key for a reliable site survey (see Tusini, 2006).

This data sheet analyses first of all the disabled person's care and social network, which includes all the players involved with them in some way,

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[7] See Data Sheet S6, Section S6.3.

[8] On the various dimensions related to autonomy at home, see § 1.5.

[9] The structure of this section is also based on other tools that deal with the social environment, adopted in Italy by Tuscany and Veneto Regional Governments.

from those who provide care and assistance to those who have established relationships of various types with them, whether family or otherwise. It also examines the relationship the disabled person, or their caregivers, establishes with the network of social and healthcare services, to explore potential access to specific information or services.

Data Sheet S4 includes five tables that guide the interview with the disabled person or their caregivers.

> In this, as in many other parts of the AdAM, the tables have two purposes: (1) to list in an organized form the topics that have to be investigated; (2) to allow data gathered in the interview to be recorded. Only in a few cases do the tables include a suggested formulation of the questions to be asked. This gives the social worker (and other members of the work group) the freedom to investigate these aspects in the manner, way and time they consider most adequate with respect to the health and the social and cultural characteristics of the people they are interviewing. It is likely, for example, that some information is already known to the work group (such as the composition of the family nucleus) and therefore it is not necessary (and can even be counterproductive) to dwell on these aspects. Moreover, certain issues can be addressed at a subsequent stage of the site survey, in order to ease the flow of communication between the work group and the disabled person.

The first table sums up the composition of the family nucleus and aims to understand which people are in the most direct, continuous relationship with the disabled person, sharing the domestic space with them. The type of relationship or degree of kinship with the disabled person is recorded, as is their age and profession. It also highlights which of these people play a primary role in the assistance and care of the disabled person (main caregivers), specifying the activities they carry out.[10]

The second table extends the previous analysis to individuals outside the family nucleus but are part of the disabled person's assistance, care and also the social relationships. Again, in this case the individuals playing a primary role in assisting the disabled person (main caregivers), the type of activity they carry out,[11] and the frequency of their meetings with the disabled person are also recorded.

A third table refers to any social activities the disabled person may engage in outside the home, specifying type and frequency. In particular, reference is made to the main activities that contribute to satisfying the person's need to participate, both to establish a more complete picture

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[10] A distinction is made, in particular, between: (1) *Activities of Daily Living – ADLs* (satisfying physiological needs, personal hygiene, dressing, eating, drinking, transfers, etc.); (2) *Instrumental Activities of Daily Living – IADLs* (cleaning, shopping, cooking, washing, etc.); (3) *Supervision Activities* (day and/or night).

[11] In this case, social interaction activities are also included.

regarding the fulfilment of those needs and for understanding how they are satisfied outside the home.

The fourth table explores the person's access to services and social networks. The purpose is to analyse if and with what frequency the disabled person or the caregiver/s relate to a series of social bodies and players that can be important in terms of access to services and information regarding disability, either institutional (social and care services and associations) or peer groups (other families or individuals with disabilities). In many cases, it is precisely the relationship with these players that gives access to opportunities, services, tools and knowledge concerning the world of disability and can contribute to increasing the well-being and autonomy of the disabled person.

The last table deals with the ways in which disabled persons (or their relatives or friends) came to know about the ADA Project. This is useful for identifying the most efficient communication channels for promoting the ADA Project and those on which to work in the future for bettering their diffusion and communication efficiency.

Data Sheet S5: Other Notes on the Disabled Person's Social and Health Profile

Data Sheet S5 includes two free text fields, in which the social and healthcare services members of the work groups can note at any moment of the site survey additional information that grows the social and health profile of the disabled person and their social environment, and which could be useful for drafting the accessibility recommendations. These fields, for example, can be used to record expected modifications to the individual's care and social network (e.g., modifications to the family nucleus) to be considered when choosing the solutions to adopt for addressing accessibility issues.

> For example, there are cases in which the caregiver who usually assists the disabled person in activities that require physical strength (such as moving a quadriplegic person from a wheelchair to bed) is elderly and will therefore become progressively less able to provide help; or in which a main caregiver (such as a brother or sister) leaves the family nucleus in the near future. In these cases, highlighting this information can be particularly important both for identification of accessibility issues and for selecting possible solutions to overcome/mitigate them.

Data Sheet S6: Analysis of the Physical Environment

This data sheet is filled out by the work group architect and is the most substantial part of the site survey.

Data Sheet S6 is composed of four sections and each one can be completed or supplemented at any time during the site survey, or even after its conclusion.

It is worth noting that since the aim of a housing adaptation is to reduce accessibility issues for *a particular person who lives in a specific care, social and physical context*, this data sheet is not based on accessibility standards.

Section S6.1 General Home Information

This section refers to information that provides a summary description of the disabled person's home and aspects related to its accessibility. Section S6.1 includes general information about the tenure status of the home, the type of residence and the construction period, as well as more specific information regarding: (1) the layout of the home; (2) outdoor access to the dwelling; (3) any existing devices for lifting and transferring the person inside the home; (4) any other adaptations already carried out, including home automation products and systems; (5) the presence of internet connection and computerised and communication devices (telephones, mobile phones, computers, TV, etc.), clarifying whether they are used directly by the disabled person and/or with the help of the caregiver/s.

The last part of this section assesses the potential vulnerability of the disabled person in case of natural disasters (floods, fires, earthquakes, etc.). These data are useful not only in terms of housing adaptations, but also for specific emergency programs/services provided by Tuscany Regional Government and Civil Protection for the evacuation of disabled persons in case of natural disasters.

Section S6.2: Other Observations on the Physical Environment

This section consists of a page for making notes on any aspects that can provide further support to knowledge of the environment and which could be useful for drafting the accessibility recommendations. This section was included because of the difficulty of foreseeing, in the structured parts of the AdAM, all possible aspects connected to accessibility and which can be important in a dwelling.

Section S6.3: Home Activities Checklist

This section originated from the necessity to facilitate the identification of the accessibility issues that interfere with the domestic life of the disabled person. By listing in brief the most common activities that can be carried out at home, the Checklist allows quick, efficient identification and recording of all the activities affected by one or more accessibility issues.

The idea of identifying accessibility issues starting from the analysis of the activities carried out in the environment – rather than from the analysis of the quality of the environment – is part of an approach that recognises the relevance of *affordances* in the relationship between people and space.

Table 5 – The classes of activities and related elementary activities adopted in the ADA Home Activities Checklist. The seven classes of basic activities are marked with an asterisk.

Classes of activity	Elementary Activities
*Reaching / leaving the home**	Reaching the entrance of the home Entering/exiting the home Other:..
*Moving inside the home**	Moving between the various levels of the home Moving between the various spaces (on the same level) Other:..
Access and enjoyment of the home's outdoor spaces	Reaching the home's outdoor spaces Moving around the home's outdoor spaces Other:..
*Eating**	Reaching the table / other equipment for eating meals Other:..
Preparing meals	Using the kitchen sink Using the stove top Using the oven Using the fridge Using the dishwasher Using the work surface Using the kitchen furniture Using other instruments for preparing meals Other:..
*Carrying out physiological needs**	Sit on the toilet Use the toilet Other:..
*Take care of personal hygiene**	Use the washbasin Transfer to the bidet/bathtub/shower Use the bidet Use the bathtub Use the shower Other:..
*Sleep/rest**	Transfer to bed and other equipment for resting Sleeping/resting Other:..
*Getting dressed**	Taking/replacing clothes from/in specific containers Other:..
Controlling environmental features	Opening/closing windows Opening gates/doors from the inside Communicating with visitors who are outside Opening/closing indoor and outdoor shading systems Controlling and managing artificial lighting Controlling and managing heating and air-conditioning systems Other:..

Classes of activity	Elementary Activities
Controlling personal safety	Controlling and managing active safety systems Using passive safety systems Other:…………………………………………………………
Communicating at a distance	Communicating inside the dwelling Communicating between the inside and the outside of the dwelling Other:…………………………………………………………
Work, study	Using an adequate chair for the work/study station Reaching the table/any other work/study station Using the tools and equipment necessary for carrying out activities Other:…………………………………………………………
Leisure activities	Using leisure spaces and equipment Playing Taking care of pets/home gardens Carrying out creative or DIY activities Other:…………………………………………………………
Carrying out domestic chores	Doing laundry (by hand or with a washing machine) Hanging clothes to dry/using the dryer Ironing Cleaning Other:…………………………………………………………
Carrying out rehabilitation activities	Carrying out motor rehabilitation activities Other:…………………………………………………………
Other	Specify:……………………………………………………
Other	Specify:……………………………………………………
Other	Specify:……………………………………………………

According to Gibson, who proposed this powerful concept (1979), *affordances* are opportunities for action mediated by the environment. Hence, if people perceive affordances according to what they do *in* and *with* space, the examination of activities is a crucial starting point for building a reliable picture of how people relate to their environment and on what hinders their relationship with it.

The Home Activities Checklist is structured as a two-level classification (Table 5). Each of its sixteen classes of activity is further divided into a series of connected elementary activities.[12]

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[12] The activities a severely disabled person can perform in their home environment can be defined using various classifications and assessment scales. The organic framework of the activities at home included in the ADA Checklist refers mainly to three sources: (1) the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001); (2) the scales of the *Activities of Daily Living* (ADLs) and *Instrumental Activities of Daily Living* (IADLs); (3) the results of an earlier research project on injuries at home (Laurìa, 2010).

As it is almost impossible to predict all possible activities at home, the Checklist offer the interviewer an opportunity to add *other activities* not originally included in the classification.

The Checklist is used in the initial part of the interview with the disabled person (and/or their caregivers) and therefore precedes and orients the subsequent analytical survey of all the accessibility issues that come to light, found in the next section of the AdAM (S6.4).

> The ADA Home Activities Checklist should therefore be considered a fact-finding tool for increasing ability to identify the accessibility issues that prevent or hinder the activities that each person carries out or would like to carry out at home. The slight redundancy and overlapping of some classes of activities increases the probability of recognising concerns and, therefore, also the possibility of addressing them in the accessibility recommendations.[13]

Of the sixteen classes of activities considered, seven are defined *basic activities*, in other words activities that every person carries out, independently of other factors. These are activities linked to physiological or well-being needs (eating, taking care of physiological needs and personal hygiene, sleeping/resting, getting dressed) or to activities required to prevent the person being confined to the dwelling (entering/exiting the dwelling, moving inside the dwelling), including in an emergency. These seven *basic activities* are carried out by all disabled people, whether autonomously or with the assistance of other people.

The Ada Project framework also classifies activities at home as:

1. *Compatible activities*, and
2. *Significant activities*.

Compatible activities are those that a disabled person is *capable* of carrying out considering their health, age and psychological development. As mentioned earlier, the analysis made using the *Modified Barthel Index*[14] is the main tool used to identify activities that the disabled person would not be able to perform in any case, regardless of the environment where they find themselves. *Significant activities,* on the other hand, are those the disabled person is *interested* in carrying out and that have a particular importance for them.

Basic activities, *compatible activities* and *significant activities* are three conceptual categories of fundamental importance for the identification of accessibility issues (as well as for case assessment, as we will see below). While accessibility issues related to *basic activities* must always be examined, it makes no sense to analyse the accessibility issues for *non-compatible activities*: those

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[13] This is the typical advantage of the so-called *fuzzy* or non-rigid classification, in which the boundaries between classes is vague and the categories overlap. On the advantages of the *fuzzy* logic in research, see Kosko (1993).

[14] See the AdAM Data Sheet S3.

activities cannot be carried out by that person, even when assisted;[15] and it would also make no sense to explore conflicts related to *non-significant activities*, which the disabled person in question has no wish to carry out.[16] As can be seen, c*ompatible activities* and *significant activities* refer to categories that are strongly and logically connected to the concept of *personalisation*, which is one of the guiding principles of the site survey and of the entire ADA Project.[17]

The identification of activities linked to accessibility issues is achieved during an interview. In the AdAM, the beginning of this section includes some examples of questions that can help start the conversation and direct the interview towards finding accessibility issues and spatially-related desires of the disabled persons or their caregivers. These are generic questions that have to be adapted according to circumstances and the social, cultural and relational needs of the participants, but they also serve to build up a relationship of trust between the work group and the participants: a relationship that is fundamental for obtaining reliable information.

> The dialogue with the disabled person (and/or with the caregiver/s) aims to find replies to the following questions: (1) "What's an average day for you?"; (2) "Which domestic activities would you like to carry out at home if you could?"; (3) "What obstacles stop you from doing what you wish?"; (4) "What would help you do what you need to do?"; (5) "Is the home care available to you enough for your needs?" (see Gray *et al.*, 2003). These questions are not voiced in a formal way, like in a structured interview, but rather as part of an informal conversation. It is important that the questions are always adapted to suit the subject. For example, in some cases questions (2), (3), and (4) can be simplified by asking: "If you had a magic wand, what would you change in your home?"

Field experience soon showed that the site survey is conducted quite differently depending on the characteristics of the disabled person (and their caregiver/s), and on the existence of a consolidated relationship between them and the work group's social and healthcare services personnel. For this reason, it is not always possible or appropriate to go through the entire Checklist searching for accessibility issues. In some cases, for example, once an accessibility issue (or a small number of accessibility issues) has been identified through the interview with the disabled person (and/or their caregivers), the in-depth analysis of each one is performed immediately by moving to the environmental unit/s where the accessibility issue occurs. In these cases, the Checklist will be consulted again later, often more than once. What is important is that at the end of the site survey no class of activity in the Checklist is overlooked when looking for accessibility issues.

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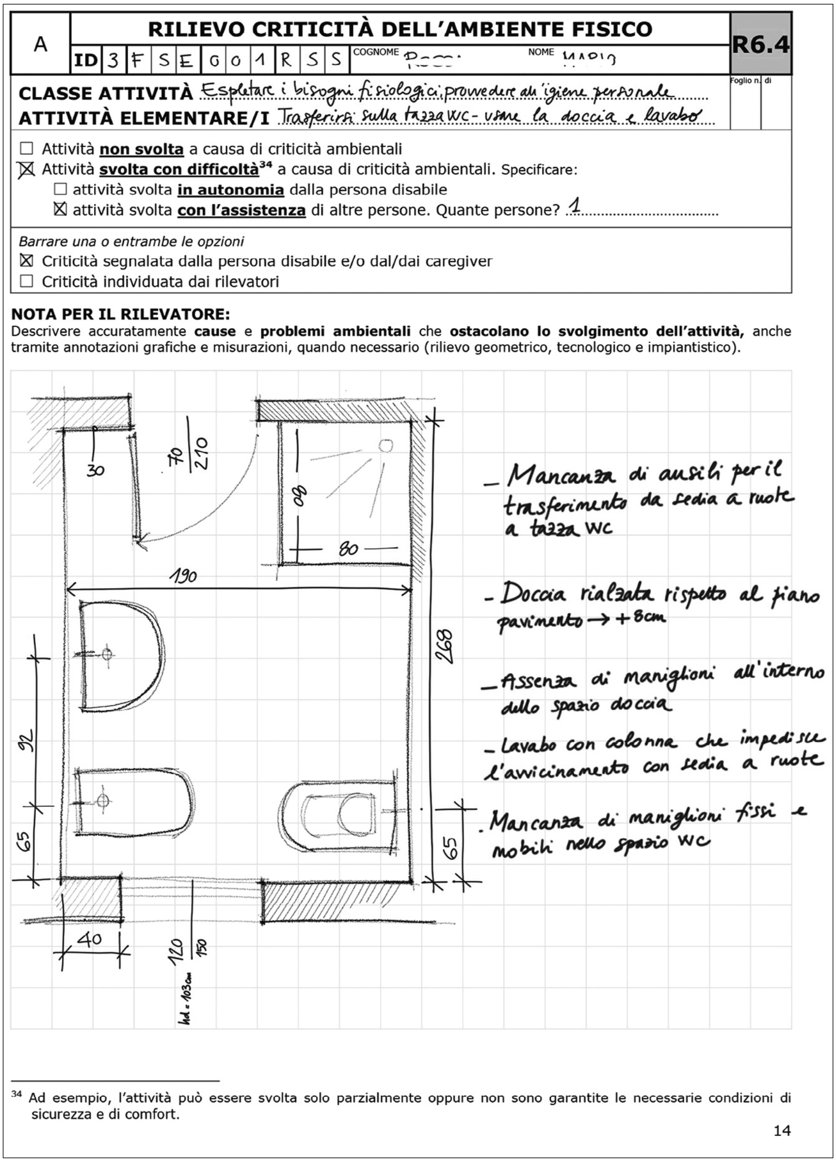
[15] Consider, for example, activities that individuals with a serious cognitive disability could not perform (such as "cooking" or "controlling environmental factors").

[16] Consider, for example, a disabled person not interested in doing things like "cooking", "taking care of a pet" or "taking care of the home garden".

[17] See § 2.2.



A	**RILIEVO CRITICITÀ DELL'AMBIENTE FISICO**	**R6.4**
	ID 3 F S E 0 0 1 R S S COGNOME [redacted] NOME [redacted]	

CLASSE ATTIVITÀ Espletare i bisogni fisiologici; provvedere all'igiene personale
ATTIVITÀ ELEMENTARE/I Trasferirsi sulla tazza WC - usare la doccia e lavabo

Foglio n. di

☐ Attività **non svolta** a causa di criticità ambientali
☒ Attività **svolta con difficoltà**[34] a causa di criticità ambientali. Specificare:
  ☐ attività svolta **in autonomia** dalla persona disabile
  ☒ attività svolta **con l'assistenza** di altre persone. Quante persone? 1

Barrare una o entrambe le opzioni
☒ Criticità segnalata dalla persona disabile e/o dal/dai caregiver
☐ Criticità individuata dai rilevatori

NOTA PER IL RILEVATORE:
Descrivere accuratamente **cause** e **problemi ambientali** che **ostacolano lo svolgimento dell'attività,** anche tramite annotazioni grafiche e misurazioni, quando necessario (rilievo geometrico, tecnologico e impiantistico).

- Mancanza di ausili per il trasferimento da sedia a ruote a tazza WC
- Doccia rialzata rispetto al piano pavimento → +8cm
- Assenza di maniglioni all'interno dello spazio doccia
- Lavabo con colonna che impedisce l'avvicinamento con sedia a ruote
- Mancanza di maniglioni fissi e mobili nello spazio WC

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[34] Ad esempio, l'attività può essere svolta solo parzialmente oppure non sono garantite le necessarie condizioni di sicurezza e di comfort.

14

Figure 20 – An example of an Accessibility Issues Survey sheet completed by the work group architect.

Section S6.4: Accessibility Issues Survey

In this section all accessibility issues identified during the interview are accurately described and analysed. For every issue (or for every elementary activity rendered problematic by one or more issues) one copy of the pages at the end of the AdAM site survey sections is to be filled out.

Each of these pages must indicate the class of activity and elementary activity to which the analysed accessibility issue refers, as well as whether the activity is made impossible by the accessibility issue/s, or whether there is simply a difficulty. In the latter, it is specified whether the activity is carried out autonomously or with the assistance of one or more caregivers. The architect also records if the accessibility issue was reported by the disabled person, the caregiver or by the architect themselves.

This page includes a large squared space that the architect can use for taking their own notes on important aspects of the accessibility issue analysed and its possible causes. In this section they can make sketches and, when necessary, check layout or technology and, if needed, use photographs or videos to illustrate the situation.

Table 6 – Site survey procedure summary of phases, activities and tasks assigned to the various work group members.

Phases	Activities and operators involved
Before the Site Survey	
Preliminaries	Immediately before the site survey starts, there is a work group briefing summing up the case to be analysed.
	Noting of possible accessibility issues that may hinder the disabled person's access to their home (verification of the path that leads from the public street to the home entrance).
	The disabled person and other members of the family nucleus (and/or external caregiver) are introduced to the work group and shown the site survey method. This is usually done by social and healthcare services personnel.
	The disabled person (or of one of their family) signs the authorisation to use and process their personal data.
During the Site Survey	
General Data	AdAM Data Sheets S1 and S2 regarding general site survey and disabled person data are filled out. Usually done by social and healthcare services personnel.
Health and Social Analysis	Filling out the AdAM Data Sheet S3 regarding analysis of the disabled person's functional limits. Done by social and healthcare services personnel.
	Filling out the AdAM Data Sheet S4 regarding the analysis of the disabled person's social environment. Done by social and healthcare services personnel.
	Filling out the AdAM Data Sheet S5, in which additional considerations regarding the social and health situation of the disabled person can be noted. Open section, conducted by social and healthcare services personnel for the entire duration of the survey.

Phases	Activities and operators involved
Analysis of the Physical Environment	Beginning of the analysis of the physical environment, AdAM Data Sheet S.6. Filling out of Section S6.1, collection of general data concerning the dwelling. Conducted by the work group architect.
	Filling out AdAM Section S6.2, where it is possible to note additional considerations regarding the home environment. Open section, conducted by the work group architect for the entire duration of the site survey.
	Filling out AdAM Section S6.3 regarding the general analysis of the accessibility issues that prevent or impede performance of domestic activities, based on the Home Activities Checklist. Analysis conducted by the work group architect.
	Filling out AdAM Section S6.4 regarding the analytical survey of the accessibility issues that emerged during the interview and/or those identified directly by the work group architect. Survey of layout/technology/plant engineering. Conducted by the work group architect.
Informative	Summary description for the benefit of the disabled person and the other members of the family nucleus (and/or the external caregiver) of the results of the site survey and of the accessibility issues identified in addition to those indicated by the disabled person (or by the members of the family nucleus or by external caregivers) during the interview. Phase conducted collectively by the work group, who then takes its leave.
After the Site Survey	
Data Check	Comparison and cross-check of data produced. Activity carried out collectively by the work group upon conclusion of the survey or immediately after.

5.3 Assessment Data Sheets

The Assessment Data Sheets are at the end of the ADA Assessment Model.

These data sheets refer to the three areas examined by the ADA Project: *Limitation of Functional Autonomy* (Data Sheet A1), *Care and Social Deficits* (Data Sheet A2), and *Accessibility Issues* (Data Sheet A3). These three areas contribute to defining the score for the disabled person's *Autonomy at Home Limitation* (Data Sheet A4).

Data Sheet A1. Limitation of Functional Autonomy Assessment

Data for the assessment of this aspect is collected during the site survey, using the *Modified Barthel Index*. It is at that point that the healthcare members of the work group assign scores to the *items* on the index and then calculate the total score, which can range from 0 to 100. This total score corresponds to one of the six levels of *Functional Autonomy* of the disabled person, ranging from *total dependence* (0–24 points) to *total self-sufficiency* (100 points).[18]

The A1 Assessment Data Sheet converts the *Disabled Person's Level of Functional Autonomy* into one of the five levels of *Limitation of Functional Autonomy* adopted by the ADA Project. These five levels correspond to five possible scores, from 0 to 20 points, with progressive increases of 5 points, as seen in Fig. 4.

SH	**LIMITATION OF FUNCTIONAL AUTONOMY ASSESSMENT**	**A1**

Indicate the level of Limitation of Functional Autonomy based on the Disabled Person's Level of Functional Autonomy (*Modified Barthel Index*, Data sheet S3), using this conversion table.

Disabled Person's Level of Functional Autonomy (*Modified Barthel Index*)		**LIMITATION OF FUNCTIONAL AUTONOMY**		
100/100	Fully independent	**NULL**	☐	**0**
91–99 /100	Almost fully independent	**SLIGHT**	☐	**5**
75–90/100	Slightly dependent			
50–74/100	Moderately dependent	**MODERATE**	☐	**10**
25–49/100	Severely dependent	**SEVERE**	☐	**15**
0–24/100	Totally dependent	**TOTAL**	☐	**20**

Figure 21 – Limitation of Functional Autonomy Assessment Data Sheet.

Data Sheet A2. Care and Social Deficits Assessment

This data sheet is for assessment of the care and social needs of the disabled person, and specifically seeks to identify deficits in fulfilment of those needs.

This assessment is based on the information gathered during the site survey, primarily through the completion of Data Sheet S4, which analyses the social environment.[19]

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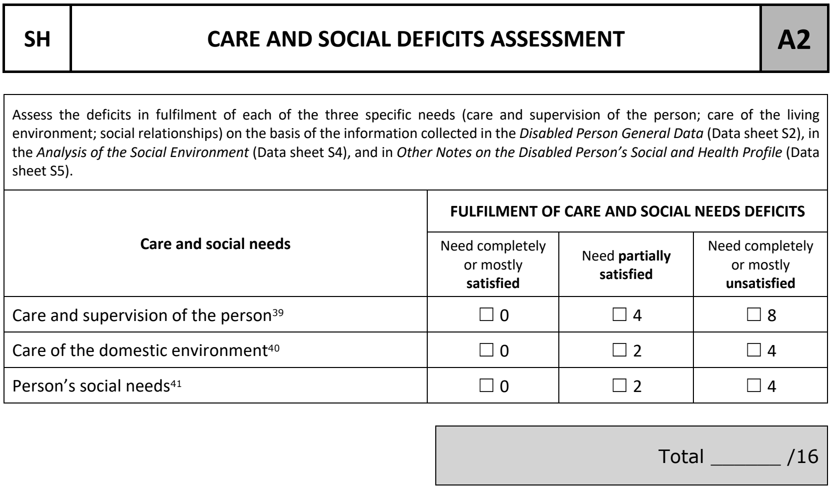
[18] These are the six levels of functional autonomy already used by healthcare personnel from Tuscany Regional Government's Multidisciplinary Assessment Units.

[19] Although to a lesser extent, other information gathered during the Site Survey can also be useful for this evaluation, in particular information contained in Data Sheet S2 (for example "General data concerning the disabled person", with information about possible socio-therapeutic and rehabilitation programmes) and Data sheet S5 ("Other notes concerning the social and health profile of the disabled person", which contains additional relevant information independently noted by social and health-care services personnel).



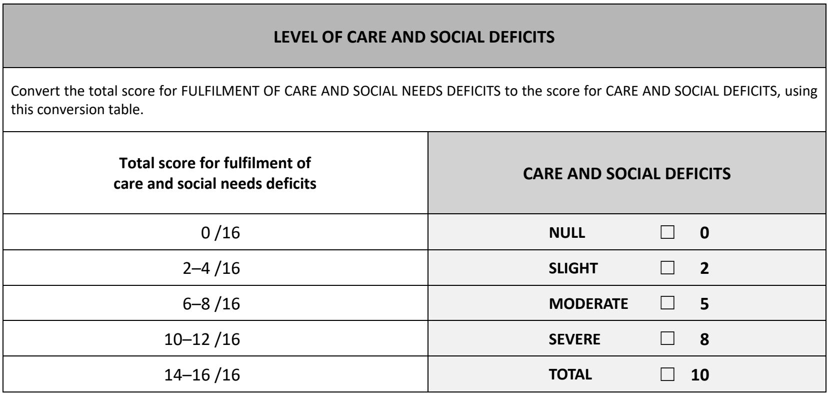
SH	**CARE AND SOCIAL DEFICITS ASSESSMENT**	**A2**

Assess the deficits in fulfilment of each of the three specific needs (care and supervision of the person; care of the living environment; social relationships) on the basis of the information collected in the *Disabled Person General Data* (Data sheet S2), in the *Analysis of the Social Environment* (Data sheet S4), and in *Other Notes on the Disabled Person's Social and Health Profile* (Data sheet S5).

Care and social needs	**FULFILMENT OF CARE AND SOCIAL NEEDS DEFICITS**		
	Need completely or mostly **satisfied**	Need **partially satisfied**	Need completely or mostly **unsatisfied**
Care and supervision of the person[39]	☐ 0	☐ 4	☐ 8
Care of the domestic environment[40]	☐ 0	☐ 2	☐ 4
Person's social needs[41]	☐ 0	☐ 2	☐ 4

Total ______ /16

Figure 22 – The first part of the Data Sheet A2, with the three care and social deficits aspects the work group has to assess.



LEVEL OF CARE AND SOCIAL DEFICITS

Convert the total score for FULFILMENT OF CARE AND SOCIAL NEEDS DEFICITS to the score for CARE AND SOCIAL DEFICITS, using this conversion table.

Total score for fulfilment of care and social needs deficits	**CARE AND SOCIAL DEFICITS**		
0 /16	**NULL**	☐	**0**
2–4 /16	**SLIGHT**	☐	**2**
6–8 /16	**MODERATE**	☐	**5**
10–12 /16	**SEVERE**	☐	**8**
14–16 /16	**TOTAL**	☐	**10**

Figure 23 – The second part of the Data Sheet A2, in which the score of the first part of the assessment is converted into one of the five levels of care and social deficit.

As already seen, that data sheet is structured in such a way as to favour as detailed a reconstruction as possible of the framework for fulfilment of the disabled person's care and social needs. Similarly, the assessment gauges to what degree the disabled person's care and social needs are satisfied (Fig. 22). In particular, three needs are considered: (1) care and supervision of the person; (2) care of the domestic environment; (3) the person's social needs.[20] After these three aspects have been assessed, the respective scores are added up to a total that can range from 0 to 16 points.

> As shown by the scores, care deficits relative to the first need are the most important due to the specific impact of the care and supervision of the disabled person when carrying out *basic activities*, both during the day and at night.

The score is then converted to gauge the level of *care and social deficits* using the five-level table found in Fig. 23. These levels, in turn, correspond to five scores, from 0 to 10 points, whose non-linear progression affords greater importance to situations of greater deficit.

Data Sheet A3. Accessibility Issues Assessment

This assessment data sheet (Fig. 24) aims to produce a summary assessment of the level of person-environment conflict. It takes into consideration the level of difficulty the disabled person (with or without caregiver/s) faces when performing the sixteen classes of activities included in the *Home Activities Checklist* (Section S6.3 of the ADA Assessment Model).[21]

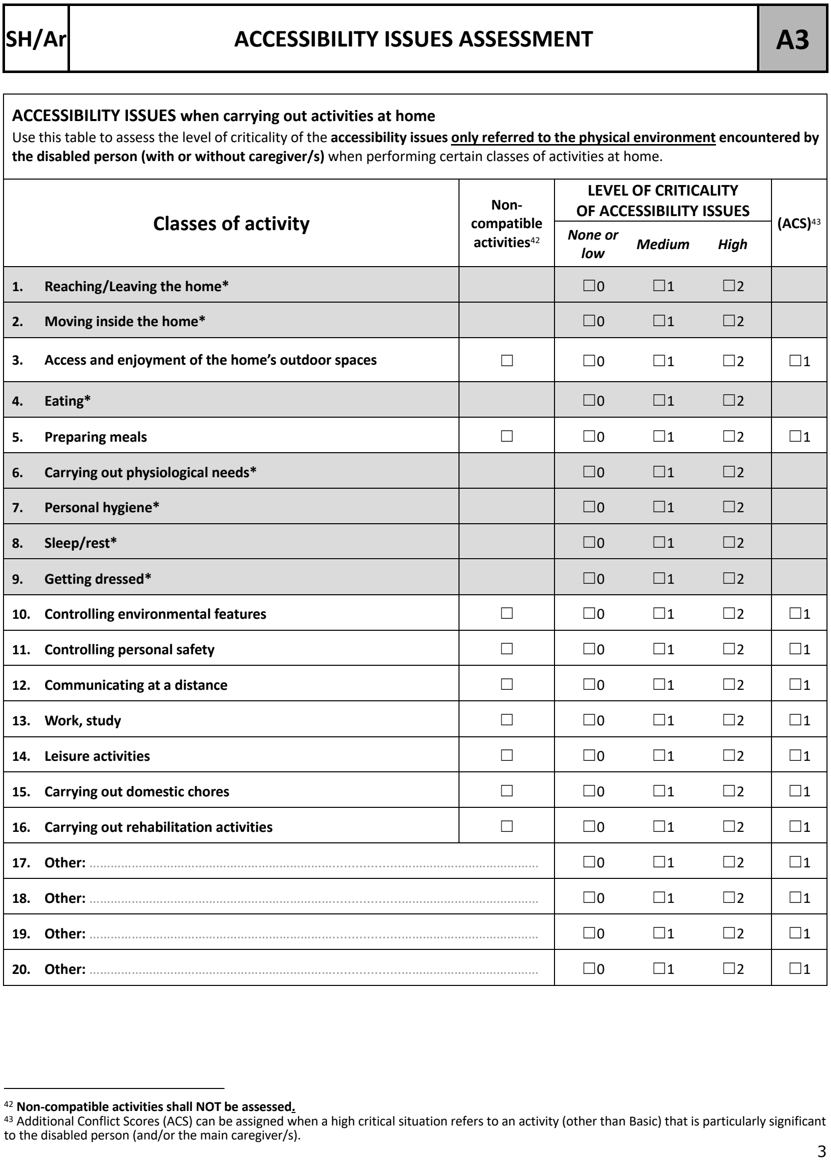
It is important to highlight that this assessment must take into account only the accessibility issues related to the dwelling, and not those that the disabled person would face anyway (for example due to their functional limitations), independently of the features of their home environment. This assessment complements the one made with the *Modified Barthel Index* (Data Sheet S3) and summarized in the assessment of the Data Sheet A1, which considered the disabled person's functional limitations in a *standard environment.* Conversely, this is an assessment of the obstacles and barriers created solely by the physical features of the dwelling. To borrow the ICF language, this sheet assesses the *performance* of persons in carrying out an activity, not their *capacities* (WHO, 2001; 2013).

As already mentioned in § 5.2, during this phase of assessment it is important to bear in mind that not all activities are *compatible* with the disabled person. For each disabled person, *compatible activities* are those they are capable of performing given their functional condition, health, age, or psychological development. For this reason, *non-compatible activities* – in other words those that the disabled person would not be able to perform anyway – are not investigated in the site survey phase nor are they assessed and are to be checked in the appropriate column in this A3 assessment data sheet.

---

[20] With the intention of making this evaluation tool easier to use, it was decided to adopt conceptual categories and a language already familiar to social and healthcare services members of the work groups.

[21] As for the site survey, the case assessment phase also allows the work group to assess other activities, initially not included in the original classification of activities.



SH/Ar	**ACCESSIBILITY ISSUES ASSESSMENT**	**A3**

ACCESSIBILITY ISSUES when carrying out activities at home

Use this table to assess the level of criticality of the **accessibility issues only referred to the physical environment encountered by the disabled person (with or without caregiver/s)** when performing certain classes of activities at home.

Classes of activity	**Non-compatible activities**[42]	**LEVEL OF CRITICALITY OF ACCESSIBILITY ISSUES**			**(ACS)**[43]
		None or low	***Medium***	***High***	
1. Reaching/Leaving the home*		☐0	☐1	☐2	
2. Moving inside the home*		☐0	☐1	☐2	
3. Access and enjoyment of the home's outdoor spaces	☐	☐0	☐1	☐2	☐1
4. Eating*		☐0	☐1	☐2	
5. Preparing meals	☐	☐0	☐1	☐2	☐1
6. Carrying out physiological needs*		☐0	☐1	☐2	
7. Personal hygiene*		☐0	☐1	☐2	
8. Sleep/rest*		☐0	☐1	☐2	
9. Getting dressed*		☐0	☐1	☐2	
10. Controlling environmental features	☐	☐0	☐1	☐2	☐1
11. Controlling personal safety	☐	☐0	☐1	☐2	☐1
12. Communicating at a distance	☐	☐0	☐1	☐2	☐1
13. Work, study	☐	☐0	☐1	☐2	☐1
14. Leisure activities	☐	☐0	☐1	☐2	☐1
15. Carrying out domestic chores	☐	☐0	☐1	☐2	☐1
16. Carrying out rehabilitation activities	☐	☐0	☐1	☐2	☐1
17. Other:		☐0	☐1	☐2	☐1
18. Other:		☐0	☐1	☐2	☐1
19. Other:		☐0	☐1	☐2	☐1
20. Other:		☐0	☐1	☐2	☐1

---

[42] **Non-compatible activities shall NOT be assessed.**

[43] Additional Conflict Scores (ACS) can be assigned when a high critical situation refers to an activity (other than Basic) that is particularly significant to the disabled person (and/or the main caregiver/s).

3

Figure 24 – Accessibility Issues Assessment Data Sheet.

Thus, work group members assess the level of criticality of the accessibility issues related to every class of *basic* and c*ompatible activities*. The assessment assigns one of the following levels of criticality: (1) none or low; (2) medium; (3) high.

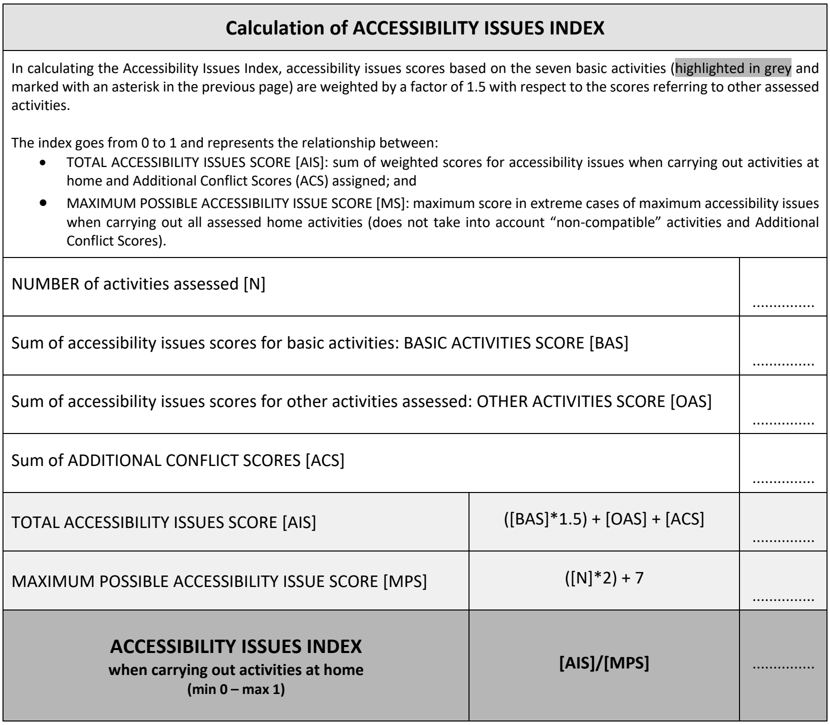
> The University of Florence research group discussed how many levels of criticality to consider for assessing accessibility issues. More levels (4 or 5, for example) improved the sensitivity of the tool but would have made it more difficult for members of the different work groups to assign scores and this would have reduced the reliability of assessments.
> Thus structured, it is possible to assess whether no accessibility issue is present or is negligible in performing the activities included in a certain class of activity (*no or low* level of criticality); whether the situation is intermediate, in other words it presents one or more accessibility issues which, however, do not substantially impede the activities (*medium* criticality); or, finally, if one or more accessibility issues substantially prevents or impedes activities (*high* criticality).
> It must be mentioned that the *no or low* criticality score is not only ascribed when no accessibility issue is present, or is negligible, but also in those cases in which a *medium* or *high* criticality is only potential, because it is related to a *non-significant activity* for the disabled person (see § 5.1.3): an activity that being of no interest for them is actually not conducted, and thus scores as *no or low* criticality.

In the phase of calculation of the *Accessibility Issues Index*, the three levels of criticality correspond respectively to 0 points (*no or low* criticality), 1 point (*medium* criticality), or 2 points (*high* criticality). In order to give greater importance to the seven classes of *basic activities*, their scores in the calculation phase are automatically weighted by a factor of 1.5. For this reason, for instance, the *high* level of criticality in the case of *basic activities* is worth 3 points, whereas for other activities it is always worth 2 points.

However, when *high* criticality is revealed in relation to an activity which may not be basic but is particularly significant for the disabled person (and/or the caregiver/s), the work group can decide to use the *Additional Criticality Score* (ACS), a tool that helps to connect with greater precision the *Accessibility Issues Assessment* with the specific characteristics and aspirations of every disabled person.

> The ACS assigns an additional point to a criticality already identified as *high*. Therefore, the score rises from 2 to 3 points, in the same way as for the *basic activities*. The ACS can be assigned, for example, when it is deemed that an accessibility issue is present in an activity that is especially important for the disabled person.
> The ACS, therefore, allows for work group discretion and may thus take into account that not all activities have the same importance for all the participants.

The criticality scores are summed up in the *Accessibility Issues Index*, which provides a brief estimate of the gravity of the person-physical conflicts in the dwelling under analysis.



Calculation of ACCESSIBILITY ISSUES INDEX

In calculating the Accessibility Issues Index, accessibility issues scores based on the seven basic activities (highlighted in grey and marked with an asterisk in the previous page) are weighted by a factor of 1.5 with respect to the scores referring to other assessed activities.

The index goes from 0 to 1 and represents the relationship between:

- TOTAL ACCESSIBILITY ISSUES SCORE [AIS]: sum of weighted scores for accessibility issues when carrying out activities at home and Additional Conflict Scores (ACS) assigned; and
- MAXIMUM POSSIBLE ACCESSIBILITY ISSUE SCORE [MS]: maximum score in extreme cases of maximum accessibility issues when carrying out all assessed home activities (does not take into account "non-compatible" activities and Additional Conflict Scores).

NUMBER of activities assessed [N]		....
Sum of accessibility issues scores for basic activities: BASIC ACTIVITIES SCORE [BAS]		....
Sum of accessibility issues scores for other activities assessed: OTHER ACTIVITIES SCORE [OAS]		....
Sum of ADDITIONAL CONFLICT SCORES [ACS]		....
TOTAL ACCESSIBILITY ISSUES SCORE [AIS]	([BAS]*1.5) + [OAS] + [ACS]	....
MAXIMUM POSSIBLE ACCESSIBILITY ISSUE SCORE [MPS]	([N]*2) + 7	....
ACCESSIBILITY ISSUES INDEX **when carrying out activities at home** **(min 0 – max 1)**	**[AIS]/[MPS]**	....

Figure 25 – Procedure for calculating the Accessibility Issues Index, as presented by the ADA Assessment Model.

The *Accessibility Issues Index* varies from 0 to 1 point. In the case of total absence of critical environmental situations, the score is 0 and it is 1 in the extreme case where all the activities evaluated (*basic* and *compatible*) present the highest degree of criticality.

As can be seen in Fig. 25 this index is calculated by dividing the total of the weighted criticality scores of every activity assessed (including the possible *Additional Criticality Scores* assigned) by the value of the sum of the criticality scores obtained in the extreme – hypothetical – case of maximum criticality in the performance of all the activities evaluated (hence, *basic* and *compatible*) for that specific disabled person.[22]

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[22] Indeed, the *Accessibility Issues Index* can hypothetically be higher than 1, as the *Additional Criticality Scores* are added to the numerator but not to the denominator. This situation, however, is highly unlikely, since it is virtually impossible that a dwelling will reveal maximum criticality levels for all the activities conducted therein.

Data Sheet A4. Autonomy at Home Limitation Score

The aspects assessed in the three previous assessment data sheets are summed up in the *Autonomy at Home Limitation Score*, calculated in the A4 Assessment Data Sheet.

When the project was in its preparatory phase, it was necessary to decide how to weight the three aspects summarised in the Autonomy at Home Limitation Score. After a series of studies within the research group and after consultation with the social and healthcare services work group members, it was decided that taking 100 as the maximum autonomy at home limitation score, the three aspects involved in its calculation should be weighted in the following proportions:

1) Limitation of functional autonomy	20/100
2) Care and social deficit	10/100
3) Accessibility issues	70/100

The proportions are strictly connected to the fact that the ADA Project, through the accessibility recommendations and the grant, specifically seeks to overcome (or, more usually, mitigate) the accessibility issues which prevent or impede the performance of activities at home. For this reason, accessibility issues are attributed with more importance in the definition of every disabled person's Autonomy at Home Limitation Score.

AUTONOMY AT HOME LIMITATION SCORE	
All disabled persons may obtain a maximum of 100 points, in these proportions: • **Limitation of functional autonomy**: max 20 points • **Care and social deficits:** max 10 points • **Accessibility issues**: max 70 points	
	SCORE
1. LIMITATION OF FUNCTIONAL AUTONOMY (max 20 points)	………….. /20
2. CARE AND SOCIAL DEFICITS (max 10 points)	…………../10
3. ACCESSIBILITY ISSUES (max 70 points)	…………../70[44]
AUTONOMY AT HOME LIMITATION SCORE **(max 100 points)**	**…………../100**

Figure 26 – Procedure for calculating Autonomy at Home Limitation Score.

As can be seen, Limitation of Functional Autonomy and Care and Social Deficits are already expressed through scores respectively reaching a maximum of 20 and 10 points. Conversely, to calculate the Autonomy at Home

Limitation Score – whose procedure is also presented in the Data Sheet A4 (Fig. 26) – it is necessary to re-calculate the values of the Accessibility Issues Index which, as may be recalled, always varies between 0 and 1. To this end, the maximum score (70 points) is given to the disabled person of each health district who obtained the highest Accessibility Issues Index. The scores of the other participants are re-calculated proportionally. This means that autonomy at home limitation scores can only be calculated after the accessibility issues of all the disabled persons entitled to the grant in a specific health district have been assessed.

Finally, the Autonomy at Home Limitation Scores allow ranking of all ADA Project participants who applied for a grant in each health district.[23]

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[23] For further information on grant assignment criteria, see § 4.3.3.

Conclusions

Antonio Laurìa

Ada is a very old and very beautiful woman's name. It is short and easy to remember and those who work in the field of accessibility know it is the acronym for a well-known US regulation on accessible design (Americans with Disabilities Act). For these reasons we were delighted when we found it could also be the acronym for the project described in this book (*Adattamento Domestico per l'Autonomia personale*, in Italian).

Thus, since 2015, for the authors of this book and for so many other people involved in the Project, ADA has become an experience of life and of work, a demanding companion that has affected all of us deeply, in terms both of knowledge and emotions.

ADA has a special place among the various research projects carried out by the *Florence Accessibility Lab* Interdepartmental Research Unit. It stands out in terms of social impact and usefulness; and it can be interpreted as a 'public good' which aspires to increase the social well-being of communities, thanks to the cultural processes it activates and to its social and educational content. Its impact can be understood by considering that so far, in addition to 362 disabled persons and their families, it involved over 100 people – among physicians, social workers, architects, sociologists, rehabilitators, experts in assistive and home automation technologies and administrative personnel – and three entities: the Tuscany Regional Government, the University of Florence and the National Research Council (CNR) in Pisa.

The ADA Project is inspired by the need to relate in a holistic perspective those areas and knowledge often interpreted and put into action separately: theory and practice; the person and their habitat; social, healthcare and design areas. Experience has shown how useful it is to establish a common language and a common basis for debate, and how much this can enhance the regional service's future capacity of response to the needs of people with severe disabilities.

Antonio Laurìa, Beatrice Benesperi, Paolo Costa, Fabio Valli, *Designing Autonomy at Home. The ADA Project. An Interdisciplinary Strategy for Adaptation of the Homes of Disabled Persons*, ISBN (online PDF) 978-88-6453-898-3,

As is well known, by connecting overall the personal conditions of the disabled to environmental factors (physical and socio-cultural) that characterise their experience of home life and that of their caregivers, housing adaptations can produce virtuous results. They make it possible to enhance the well-being of the disabled and of their caregivers (whether family members or professionals), limiting the need for assistance measures at home. Last but not least, they delay forms of institutionalisation that are variously efficient or welcome. This allows the disabled person to continue to enjoy their domestic space, family memories, and the affection of their relatives, friends and community.

Beyond the economic contribution provided (which is relatively limited), the experience of the ADA Project reveals a hidden yet not insignificant value. It expresses the closeness of Regional institution to persons and families often in distress, while also offering accessibility recommendations which, in addition to being a professional document with an economic value of its own, also have cultural significance that is not always evident to most of the possible participants in the ADA Project at the moment of its application. Indeed, the accessibility recommendations contribute to growing the *culture of accessibility* not only among its beneficiaries, but also among the various different professionals engaged in its implementation.

As this stage of the ADA Project draws to a close, I believe we can say that the goals set at the beginning have been essentially accomplished. The methodological design, which was duly adapted as a result of the experiences acquired in the field, proved to be adequate and efficient; the ADA Assessment Model, which is the main scientific product of the research, has been seen to be a trustworthy, flexible instrument.

This said, the authors are aware that the ADA Project has margins for improvement, like all innovative intervention models. Although the ADA Project has been given a positive assessment by its participants,[1] additional indications and suggestions for improvement may emerge from the ex-post evaluation, which will be undertaken when the adaptation interventions are completed and have begun to produce effects on the lives of disabled persons and their caregivers who participated in the ADA Project.

---

[1] As evidence of the climate of hope and of mutual trust that developed during the ADA Project pilot phase, I wish to quote from a letter sent by the mother of a disabled child to her local health service: “First of all I wish to thank all the people we have met over these past few months and with whom we have talked about our difficulties; their advice was very useful and their expertise enlightened us on a series of activities that we, as parents, then carried out and will continue to carry out in the future for the benefit of our child [...] It was a welcome development for us to meet people who both understood our difficulties in coping with disability and were also so highly competent in every technical aspect involved”. For additional testimonies visit: <http://open.toscana.it/web/toscana-accessibile/-/l-esperienza-del-progetto-ada-nel-video-testimonianza-dei-genitori-di-niccolo-michela-e-jury> (in Italian; last access: 01/2019).

ANNEXE

The ADA Assessment Model – AdAM

REGIONE TOSCANA

ADA Project – Housing Adaptation for Personal Autonomy

ADA ASSESSMENT MODEL

NOTE FOR THE WORK GROUP

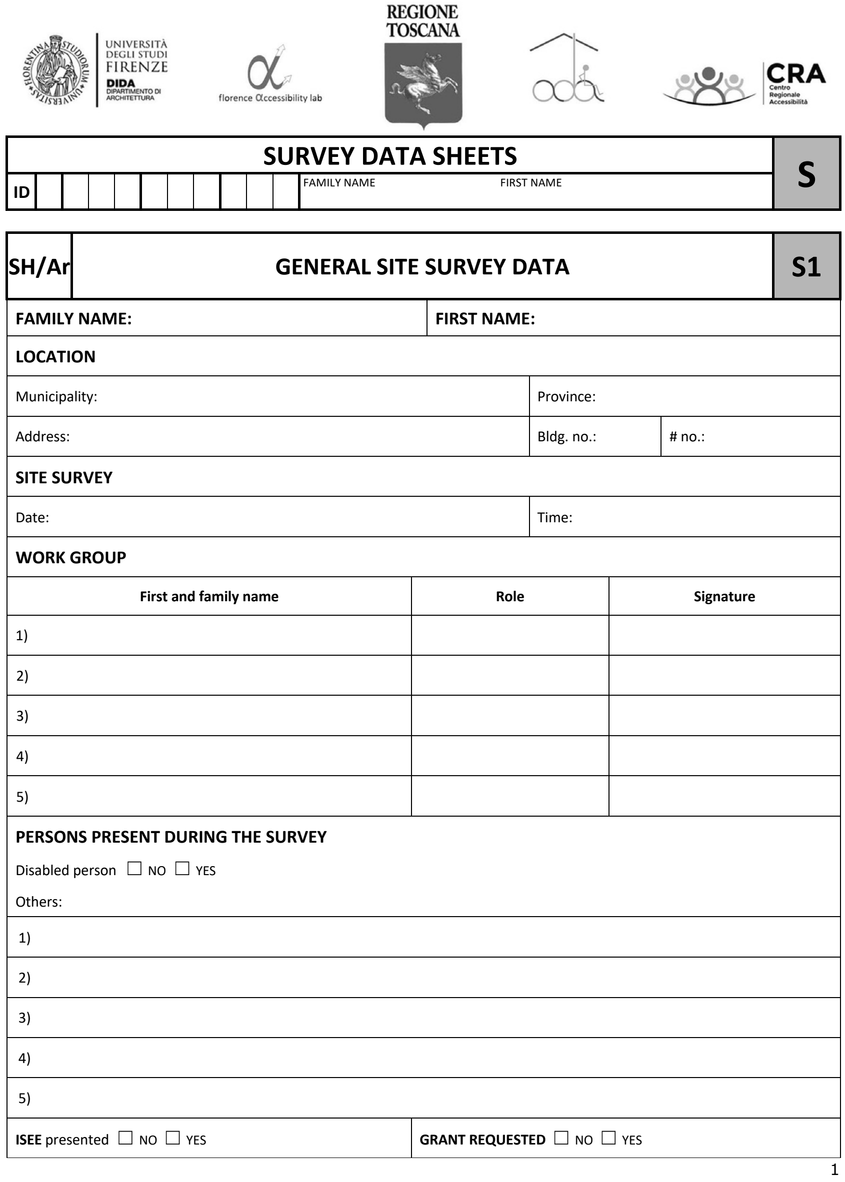
1) Symbols from S1 to S6 and from A1 to A4 in the upper right section of each data sheet indicate progressive data sheet numbering.

2) Symbols (SH, Ar, SH/Ar) in the upper left section of each data sheet indicate:

- *SH = data sheet to be completed by the social and healthcare services work group members (i.e.: social worker, physician, physiotherapist, etc.);*
- *Ar = data sheet to be completed by the architect;*
- *SH/Ar = data sheet to be completed by the social and healthcare services team members and by the architect.*

3) The ADA Project participant's alphanumeric ID code must be entered in "ID" section.

Antonio Laurìa, Beatrice Benesperi, Paolo Costa, Fabio Valli, *Designing Autonomy at Home. The ADA Project. An Interdisciplinary Strategy for Adaptation of the Homes of Disabled Persons*, ISBN (online PDF) 978-88-6453-898-3,



REGIONE TOSCANA

SURVEY DATA SHEETS		**S**
ID	FAMILY NAME FIRST NAME	

SH/Ar	**GENERAL SITE SURVEY DATA**	**S1**

FAMILY NAME:	**FIRST NAME:**	
LOCATION		
Municipality:	Province:	
Address:	Bldg. no.:	# no.:
SITE SURVEY		
Date:	Time:	
WORK GROUP		
First and family name	**Role**	**Signature**
1)		
2)		
3)		
4)		
5)		

PERSONS PRESENT DURING THE SURVEY

Disabled person ☐ NO ☐ YES

Others:

1)

2)

3)

4)

5)

ISEE presented ☐ NO ☐ YES

GRANT REQUESTED ☐ NO ☐ YES

1

SH	**DISABLED PERSON GENERAL DATA**	**S2**

Place of birth:	**Date of birth**:	**Age**:

Diagnosis, type of disability and other information useful for proposing housing adaptation solutions:

....

....

....

Use of aids,[1] braces,[2] prostheses,[3] medical devices[4]

☐ NO ☐ YES, specify: ....

....

....

Progressive nature of the pathology and functional limitations:

☐ STABLE ☐ PROGRESSIVE, specify: ....

....

....

Level of education: ☐ None ☐ Elementary ☐ Middle ☐ High ☐ University degree/postgraduate degree

Current study/work situation

Study	☐ Yes, specify:	-->	Studies at home?	☐ Yes
	☐ NO			☐ No
Work	☐ Yes, specify:	-->	Works in the home?	☐ Yes
	☐ NO -->☐ Retired ☐ Unemployed ☐ Has never worked			☐ No
	Most recent employment:			

Social-therapeutic program:[5] ☐ NO ☐ YES, specify: ....

....

....

Social integration program:[6] ☐ NO ☐ YES, specify: ....

....

....

Other active services:[7] ☐ NO ☐ YES, specify: ....

....

....

---

[1] i.e.: wheelchair, crutches, etc.

[2] i.e.: collar, corset, etc.

[3] i.e.: artificial limb, etc.

[4] i.e.: pacemaker, PEG/PEJ system, mechanical ventilator, etc.

[5] i.e.: integration at work.

[6] i.e.: attends day centre, workshops, etc.

[7] i.e.: assistance at home, regional "Independent Life" program, etc.

SH	**ANALYSIS OF THE DISABLED PERSON'S LEVEL OF AUTONOMY**[8]	**S3**

For assessment purposes, refer to the disabled person's **functional situation** considered in a **standard environment**. Do not consider possible home accessibility issues as they will be assessed in Data Sheet S6, Section S6.3.	
FEEDING	
Able to feed self from a tray or table when someone puts the food within reach. Able to put on an assistive device, cut the food, use salt and pepper, spread butter, etc.	☐ 10
Independent in feeding with prepared tray except perhaps to cut meat, open milk carton, jar lid etc. Presence of another person is not required.	☐ 8
Able to feed with supervision. Assistance is required with associated tasks such as putting milk/sugar into tea, use salt and pepper, spreading butter, turning a plate or other "set-up" activities.	☐ 5
Can manipulate an eating device, usually a spoon, but someone must provide active assistance during the meal.	☐ 2
Dependent in all aspects. Needs to be fed by someone else (e.g., spoon-fed, nasogastric intubation - NGT -, percutaneous endoscopic gastronomy - PEG -, etc.).	☐ 0
BATHING SELF/SHOWERING SELF	
May use a bathtub, a shower, or take a complete sponge bath. Able to do all the steps of whichever method is employed without another person being present.	☐ 5
Supervision is required for safety (transfers, adjustment of the water temperature, etc.).	☐ 4
Help/assistance is required with either transfer to shower/bath or with washing or drying.	☐ 2
Help/assistance is required in all aspects of bathing/showering.	☐ 1
Total dependence in bathing self/showering self.	☐ 0
PERSONAL HYGIENE AND GROOMING	
Can wash his/her hands and face, comb hair, clean teeth and shave. A man may use any kind of razor without help, including manipulation. A woman must apply her own make-up, if used, but need not to style her hair.	☐ 5
Able to conduct his/her own personal hygiene but requires minimal assistance before and/or after the operation.	☐ 4
Help is required in one or more steps of personal hygiene.	☐ 2
Help is required in all steps of personal hygiene.	☐ 1
Unable to attend to personal hygiene, dependent in all aspects.	☐ 0
DRESSING	
Able to put on, remove, and properly fasten clothing, put on and take off shoes, tie shoe-laces, put on or remove corset, braces, as prescribed.	☐ 10
Only minimal help is required in some aspects, such as use of buttons, zips, bra and shoelaces.	☐ 8
Help is needed in putting on, and/or removing any clothing.	☐ 5
Able to participate to some degree, but dependent in all aspects.	☐ 2
Dependent in all aspects and unable to participate in the activity.	☐ 0
BOWEL CONTROL	
Can control bowels and has no accidents, can use suppository, or take an enema when necessary.	☐ 10
May require supervision with the use of suppository or enema; occasional accidents.	☐ 8
Can assume appropriate position, but cannot use facilitatory techniques, or clean self without assistance and has frequent accidents. Assistance is required with incontinence aids such as pads, etc.	☐ 5
Needs help to assume appropriate position, and with bowel movement facilitatory techniques.	☐ 2
Incontinent.	☐ 0
BLADDER CONTROL	
Able to control bladder day and night, and/or independent with internal or external devices.	☐ 10
Generally dry by day and night, but may have an occasional accident, or need minimal assistance with internal or external devices.	☐ 8
Generally dry by day, but not at night, and needs some assistance with the devices.	☐ 5
Incontinent but able to assist with the application of an internal or external device.	☐ 2
Incontinent or has indwelling catheter. Dependent for the application of internal or external devices.	☐ 0

---

[8] Section based on the Modified Barthel Index (Shah *et al.*, 1989), with minor terminology modifications.

USE OF TOILET AND TRANSFERS		
Able to get on and off the toilet, fasten and unfasten clothes, prevent soiling of clothes and use toilet paper without help. If necessary, may use a bedpan or commode, or urinal at night, but must be able to empty it, and clean it.		☐ 10
Supervision required for safety with normal toilet. A commode may be used at night but assistance is required for emptying and cleaning.		☐ 8
Help required with management of clothing, transferring, and washing hands.		☐ 5
Help required in all aspects.		☐ 2
Fully dependent.		☐ 0
BED - CHAIR (OR WEELCHAIR) TRANSFERS (complete also in case of a totally bedridden person)		
Independent in all phases of the transfer. Can safely approach the bed in a wheelchair, lock the brakes, lift the footrests, move safely to bed, lie down, come to a sitting position on the side of the bed, change the position of the wheelchair, transfer back into it safely.		☐ 15
The presence of another person is required either as a confidence measure, or to provide supervision for safety.		☐ 12
The transfer requires the assistance of one other person. Assistance may be required in any aspect of the transfer.		☐ 7
Able to participate but maximum assistance of one other person is required in all aspects of the transfer.		☐ 3
Unable to participate in a transfer. Two attendants are required to transfer the person with or without a mechanical device.		☐ 0
AMBULATION	**WEELCHAIR MANAGEMENT** (use this scale only if the person has a score of **zero** in the "Ambulation" scale)	
Able to wear braces if required, lock and unlock these braces, assume standing position, sit down, and place the necessary aids into position for use. Able to use crutches, canes, or a walkerette, and walk 50 metres without help or supervision.		☐ 15
Independent in ambulation but unable to walk 50 metres without help, or supervision is needed for confidence or safety in hazardous situations.		☐ 12
Requires the assistance of one person for reaching aids and/or their manipulation.		☐ 8
	Capable of ambulating autonomously (go around comers, turn around, manoeuvre the chair to a table, bed, toilet, etc.). Capable of moving at least 50 metres.	☐ 5
	Capable of ambulating autonomously for a reasonable duration over regularly encountered terrain. Minimal assistance may still be required in "tight comers".	☐ 4
Constant presence of one or more assistants is required during ambulation.	Presence of one person is necessary and constant assistance is required to manipulate chair to table, bed etc.	☐ 3
	Capable of ambulating for short distances on flat surface, but assistance is required for all other steps of wheelchair management.	☐ 1
Dependent in ambulation.	Dependent in wheelchair ambulation.	☐ 0
USE OF STAIRS		
Able to go up and down a flight of stairs safely without help or supervision. Able to use hand rails, cane, or crutches when needed and able to carry these devices as he/she ascends or descends.		☐ 10
Generally no assistance is required. At times, supervision is required for safety (e.g. due to morning stiffness, shortness of breath etc.).		☐ 8
Able to ascend/descend the stairs but unable to carry walking aids. Needs supervision and assistance.		☐ 5
Help is required in all aspects of stairclimbing (including assistance with walking aids).		☐ 2
Unable to go up and down the stairs.		☐ 0

MODIFIED BARTHEL INDEX	____ /100

SH	**ANALYSIS OF THE SOCIAL ENVIRONMENT**	**S4**

CARE AND SOCIAL NETWORK

The care and social network includes those who are part of the person's sphere and provide **assistance**, **care** or **social interaction**, both family members and outsiders.

DISABLED PERSON'S FAMILY NUCLEUS

List the people who currently live in the disabled person's home.

Kinship/relation[9]	**Age**	**Profession**	**Main caregivers** [10]	**Assists with**[11]		
				ADLs	IADLs	Supervis.
			☐	☐	☐	☐
			☐	☐	☐	☐
			☐	☐	☐	☐
			☐	☐	☐	☐
			☐	☐	☐	☐
			☐	☐	☐	☐
			☐	☐	☐	☐
			☐	☐	☐	☐

NON-FAMILY MEMBERS

Indicate individuals that do not live with the disabled person but offer assistance, care and social relations at home (relatives, neighbours, friends, volunteers, support administrator, etc.).

Description	**Main caregivers** [12]	**Assists with**				**Frequency**			
		ADLs	IADLs	Supervision	Socialisation	Once or more a day	Once or more a week	1 to 3 times a month	Less than once a month
	☐	☐	☐	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐	☐	☐	☐

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[9] Kinship/relation: husband, wife, partner, father, mother, brother, sister, grandfather/mother, son-in-law/daughter-in-law, other relative, family assistant/caregiver, other (specify).

[10] Indicate the individuals/s in the family nucleus who play a primary role in the assistance and care of the disabled person.

[11] Mention whether the indicated person takes care of Activities of Daily Living (ADLs) (physiological needs, personal hygiene, dressing, feeding, drinking, moving, etc.) and/or Instrumental Activities of Daily Living (IADLs) (cleaning, shopping, cooking, washing, etc.) and/or supervision (daytime and/or nighttime).

[12] Indicate non-family members who play a primary role in the assistance and care of the disabled person.

MAIN SOCIAL ACTIVITIES OUTSIDE THE HOME

Indicate the main activities outside the home that contribute to satisfying the disabled person's social needs, specifying the type of activity and frequency.

Description	Frequency			
	Once or more a day	Once or more a week	1–3 times a month	Less than once a month
Voluntary work, specify: …………………………………………	☐	☐	☐	☐
Sport, specify: …………………………………………	☐	☐	☐	☐
Other, specify: …………………………………………	☐	☐	☐	☐
Other, specify: …………………………………………	☐	☐	☐	☐
Other, specify: …………………………………………	☐	☐	☐	☐

ACCESS TO DISABILITY SERVICES AND SOCIAL NETWORKS

Excluding the ADA Project, was the disabled person (or main caregiver/s) in contact with the following disability services/social networks during the past 12 months? If so, how frequently?

Services /networks	Frequency during the past 12 months		
	Never	Once or twice	More than twice
Public social and healthcare services	☐	☐	☐
Associations involved in support for the disabled	☐	☐	☐
Other families or individuals with disability	☐	☐	☐
Other specify: …………………………………………	☐	☐	☐

HOW DID YOU FIND OUT ABOUT THE ADA PROJECT?

You may select more than one option

☐ Contact with social and healthcare services	☐ Relatives
☐ Information material (brochures, posters, etc.)	☐ Friends
☐ Facebook	☐ Other disabled persons
☐ The "Toscana Accessibile" portal	☐ Disability/accessibility associations
☐ Television (newscast, other services)	☐ Disability help desk
☐ Radio	☐ Other: …………………………………………

6

SH	**OTHER NOTES ON THE DISABLED PERSON'S SOCIAL AND HEALTH PROFILE**	**S5**

Use this space to note any additional remarks for the purposes of the accessibility recommendations so as to improve the description of the disabled person's social and health profile, and social environment.
For example, mention whether there are plans to modify the applicant's care and social network or to address disability progression.

SOCIAL PROFILE NOTES

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Ar	**ANALYSIS OF THE PHYSICAL ENVIRONMENT**	**S6**
	ID FAMILY NAME FIRST NAME	

Ar	**GENERAL HOME INFORMATION**	**S6.1**

TYPE OF OCCUPANCY

☐ **OWNER**	☐ **RENTER**	☐ **FREE LOAN**
☐ Full	☐ In private building	☐ **OTHER** specify: ....
☐ Partial	☐ In public building	....

TYPE OF DWELLING

☐ **Multi-family building** (e.g.: semi-detached house, terraced house, block of flats, etc.)

☐ **Single-family building** (e.g.: detached house, mansion, etc.)

☐ **Other** (specify type): ....

YEAR OF CONSTRUCTION

☐ **pre-1989**[13] ☐ **post-1989**

NUMBER OF FLOORS: ☐ 1 ☐ 2 ☐ 3 ☐ ......

LAYOUT

ENVIRONMENTAL UNITS[14]

INDOOR	**OUTDOOR**
Indicate the main indoor environments (i.e.: kitchen, two bedrooms, living room, entrance, bathroom, cellar, etc.)	Indicate main outdoor spaces (i.e.: two balconies, garden, courtyard, etc.)
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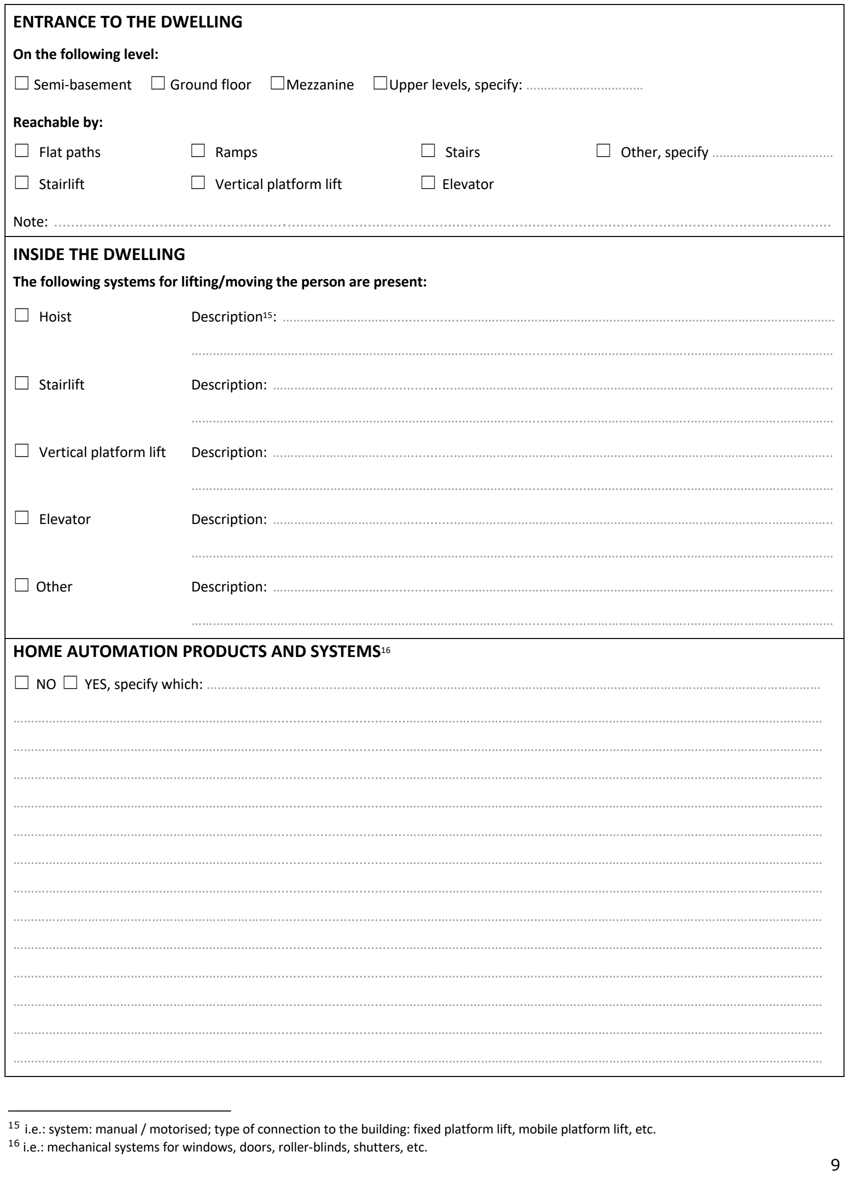
[13] Italian Ministerial Decree 236, which defines standards for the elimination of architectural barriers in private buildings, came into force in 1989.

[14] Italian Standard UNI 10838:1999 defines an "environmental unit" as a grouping of spatially and temporally compatible user activities determined by the building's intended use. These environmental units include bedroom, living room, kitchen, etc.



ENTRANCE TO THE DWELLING

On the following level:

☐ Semi-basement ☐ Ground floor ☐Mezzanine ☐Upper levels, specify: ……………………………

Reachable by:

☐ Flat paths ☐ Ramps ☐ Stairs ☐ Other, specify ……………………………

☐ Stairlift ☐ Vertical platform lift ☐ Elevator

Note: ……

INSIDE THE DWELLING

The following systems for lifting/moving the person are present:

☐ Hoist Description[15]: ……………………………………………………………………………………
……………………………………………………………………………………………………

☐ Stairlift Description: ……………………………………………………………………………………
……………………………………………………………………………………………………

☐ Vertical platform lift Description: ……………………………………………………………………………………
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☐ Elevator Description: ……………………………………………………………………………………
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☐ Other Description: ……………………………………………………………………………………
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HOME AUTOMATION PRODUCTS AND SYSTEMS[16]

☐ NO ☐ YES, specify which: ……………………………………………………………………………………
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[15] i.e.: system: manual / motorised; type of connection to the building: fixed platform lift, mobile platform lift, etc.

[16] i.e.: mechanical systems for windows, doors, roller-blinds, shutters, etc.

INTERNET CONNECTION IN THE DWELLING

☐ NO ☐ YES, specify:
- ☐ Network cable
- ☐ WIFI
- ☐ Other ……………………………………………………………………………………

COMMUNICATION AND IT DEVICES

Indicate the devices present in the dwelling and whether they are used by the disabled person and/or the main caregiver

Device	Presence	Use	
		Disabled person	**Caregiver** (optional)
Landline (wired)	☐	☐	☐
Landline (cordless)	☐	☐	☐
Mobile phone	☐	☐	☐
Smartphone	☐	☐	☐
Tablet	☐	☐	☐
Desktop PC	☐	☐	☐
Laptop computer	☐	☐	☐
TV	☐	☐	☐
Smart TV	☐	☐	☐
Other, specify: ……………………………………………	☐	☐	☐
Other, specify: ……………………………………………	☐	☐	☐

DISABLED PERSON IN A PARTICULARLY VULNERABLE CONDITION IN CASE OF AN EMERGENCY

(i.e.: FLOOD, FIRE, EARTHQUAKE, etc.)

☐ NO ☐ YES If YES, specify[17]: ……………………………………………………………

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[17] Always relate the disabled person to the environmental context. For example: person with motor difficulties who lives on a floor other than the ground level in an area at earthquake risk; person confined to bed who lives on the ground floor in a flood-prone area; person who lives on a street that is difficult for emergency transport services to access, etc. If this is the case also highlight any possible deficits in terms of care and assistance in the event of a natural disaster. In general, this information does not concern domestic adaptation directly, but rather specific emergency programs/services provided by Tuscany Regional Government and Civil Protection for the evacuation of disabled persons in case of natural disasters.

Ar	**OTHER OBSERVATIONS ON THE PHYSICAL ENVIRONMENT**	**S6.2**

Use this space for any site survey remarks on the disabled person’s physical environment to add detail to the accessibility recommendations.

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Ar	**HOME ACTIVITIES CHECKLIST**	**S6.3**

NOTE FOR DATA COLLECTOR

In an interview intended to identify accessibility issues, it can be a good idea to ask questions using an informal approach, for instance: “What do you do on an average day?”, “Which domestic activities would you like to carry out at home if you could?”, “What obstacles stop you from doing what you wish?”, “What would help you do what you need?”, “Is the home care available to you enough for your needs?” (Alternatively, the questions can be simplified: “If you had a magic wand, what would you change in your house?”).

Activities are understood to be actions performed **autonomously** and/or **with the assistance/support of other people.**

Identify accessibility issues f related only to **compatible**[18] and **significant**[19] activities. The items related to the seven classes of **basic activities**[20] are marked with an asterisk (*).

Classes of activity	Elementary activities which present issues
1. Reaching/leaving the home*	☐ A. Reaching the entrance of the home ☐ B. Entering/exiting the home ☐ C. Other: ....
2. Moving inside the home*	☐ A. Moving between the various levels of the home ☐ B. Moving between the various spaces (on the same level) ☐ C. Other: ....
3. Access and enjoyment of the home’s outdoor spaces[21]	☐ A. Reaching the home’s outdoor spaces ☐ B. Moving around the home’s outdoor spaces ☐ C. Other: ....
4. Eating*	☐ A. Reaching the table/other equipment for eating meals ☐ B. Other: ....
5. Preparing meals	☐ A. Using the kitchen sink ☐ B. Using the stove top ☐ C. Using the oven ☐ D. Using the fridge ☐ E. Using the dishwasher ☐ F. Using the work surface ☐ G. Using kitchen furniture ☐ H. Using other instruments for preparing meals ☐ I. Other: ....
6. Carrying out physiological needs*	☐ A. Sit on the toilet ☐ B. Use the toilet ☐ C. Other: ....
7. Take care of personal hygiene*	☐ A. Use the washbasin ☐ B. Transfer to the bidet/bathtub/shower ☐ C. Use the bidet[22] ☐ D. Use the bathtub ☐ E. Use the shower ☐ F. Other: ....
8. Sleep/rest*	☐ A. Transfer to bed and other equipment for resting ☐ B. Sleeping/resting ☐ C. Other:..
9. Getting dressed*	☐ A. Taking/replacing clothes from/in specific containers[23] ☐ B. Other: ....

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[18] *Compatible activities* are those that the disabled person can carry out given their functional condition, age and psychological development.

[19] *Significant activities* are those that the disabled person would like to carry out, as well as those that are important for their safety and integrity.

[20] *Basic activities* are those that every person carries out, independently of other factors. These are activities linked to physiological or well-being needs, or to activities required to prevent the person being confined to the dwelling (entering/exiting the dwelling, moving inside the dwelling), including in an emergency. These are carried out by all disabled people, whether autonomously or with the assistance of other people.

[21] i.e.: balconies, terraces, porticoes, gardens, courtyards, etc., for exclusive or collective use.

[22] Or WC shower, toilet bowl or toilet cover with bidet, etc.

[23] i.e.: cabinets, wardrobe, chest of drawers, etc.

Classes of activity	Elementary activities which present issues
10. Controlling environmental features	☐ A. Opening/closing windows ☐ B. Opening gates/doors from the inside ☐ C. Communicating with visitors who are outside ☐ D. Opening/closing indoor[24] and outdoor[25] shading systems ☐ E. Controlling and managing artificial lighting ☐ F. Controlling and managing heating and air-conditioning systems ☐ G. Other: ……………………………………
11. Controlling personal safety	☐ A. Controlling and managing active safety systems[26] ☐ B. Using passive safety systems[27] ☐ C. Other: ……………………………………
12. Communicating at a distance	☐ A. Communicating inside the dwelling[28] ☐ B. Communicating between the inside and the outside of the dwelling[29] ☐ C. Other: ……………………………………
13. Work, study	☐ A. Using an adequate chair for the work/study station ☐ B. Reaching the table/any other work/study station ☐ C. Using the tools and equipment[30] necessary for carrying out activities ☐ D. Other: ……………………………………
14. Leisure activities	☐ A. Using leisure spaces and equipment[31] ☐ B. Playing[32] ☐ C. Taking care of pets[33]/home gardens[34] ☐ D. Carrying out creative[35] or DIY activities[36] ☐ E. Other: ……………………………………
15. Performance of domestic chores	☐ A. Doing laundry (by hand or by washing machine) ☐ B. Hanging clothes to dry/using the dryer ☐ C. Ironing ☐ D. Cleaning[37] ☐ E. Other: ……………………………………
16. Performance of rehabilitation activities	☐ A. Carrying out motor rehabilitation activities ☐ B. Other: ……………………………………
17. Other	☐ Specify: ……………………………………
18. Other	☐ Specify: ……………………………………
19. Other	☐ Specify: ……………………………………
20. Other	☐ Specify: ……………………………………

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[24] i.e.: curtains, screens, etc.

[25] i.e.: roller blinds, shutters, etc.

[26] i.e.: systems for sending urgent messages to the exterior in case of emergency.

[27] i.e.: devices for the control and automatic signaling of irregularities (flooding, gas leaks, fires), anti-intrusion systems, environmental audio and visual systems for monitoring the person from both inside and outside the dwelling, systems for remote control of access point and signaling doors being opened, systems for automatically signaling outside the dwelling that the person has fallen or suddenly taken ill etc.

[28] i.e.: communicating with the intercom.

[29] i.e.: communicating in real time or otherwise, via audio, video, image or text messages, using the phone/SMS/chat/e-mail or other systems available for that purpose.

[30] i.e.: IT devices (computer, tablet, smartphone, printer, etc.).

[31] i.e.: electronic devices (TV, music players, etc.)

[32] i.e.: with objects or the environment.

[33] i.e.: feeding and caring for pets.

[34] i.e.: pot plants, garden, vegetable patch, etc.

[35] i.e.: painting, playing music, etc.

[36] i.e.: sewing, carpentry, pottery, etc.

[37] i.e.: using the vacuum cleaner or other appliances for home cleaning.

Ar	**ACCESSIBILITY ISSUES SURVEY**		**S6.4**
	ID	FAMILY NAME FIRST NAME	

CLASS OF ACTIVITY.. PAGE N. OF

ELEMENTARY ACTIVITY/IES ....

☐ Activity **not carried out** due to accessibility issues

☐ Activity **carried out with difficulty**[38] due to accessibility issues. Specify:

- ☐ activity carried out **autonomously** by the disabled person
- ☐ activity carried out **with the assistance** of other people. How many? ....

Check one or both options

- ☐ Accessibility issue signalled by the disabled person and/or the caregiver/s
- ☐ Accessibility issue signalled by the data collectors

NOTE FOR THE DATA COLLECTOR:
*Describe accurately the **causes** and **accessibility issues** that **hinder or prevent the activity being carried out,** also through sketches and measurements, and when necessary a survey.*

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[38] For example, an activity only partially performed or necessary safety and comfort conditions not ensured.

15

ASSESSMENT DATA SHEETS		**A**
ID	FAMILY NAME	FIRST NAME

To be filled out only for grant applicants

SH	**LIMITATION OF FUNCTIONAL AUTONOMY ASSESSMENT**	**A1**

Indicate the level of Limitation of Functional Autonomy based on the Disabled Person's Level of Functional Autonomy (*Modified Barthel Index*, Data sheet S3), using this conversion table.

Disabled Person's Level of Functional Autonomy (*Modified Barthel Index*)		**LIMITATION OF FUNCTIONAL AUTONOMY**		
100/100	Fully independent	**NULL**	☐	**0**
91–99 /100	Almost fully independent	**SLIGHT**	☐	**5**
75–90/100	Slightly dependent			
50–74/100	Moderately dependent	**MODERATE**	☐	**10**
25–49/100	Severely dependent	**SEVERE**	☐	**15**
0–24/100	Totally dependent	**TOTAL**	☐	**20**

SH	CARE AND SOCIAL DEFICITS ASSESSMENT	A2

Assess the deficits in fulfilment of each of the three specific needs (care and supervision of the person; care of the living environment; social relationships) on the basis of the information collected in the *Disabled Person General Data* (Data sheet S2), in the *Analysis of the Social Environment* (Data sheet S4), and in *Other Notes on the Disabled Person's Social and Health Profile* (Data sheet S5).

Care and social needs	FULFILMENT OF CARE AND SOCIAL NEEDS DEFICITS		
	Need completely or mostly **satisfied**	Need **partially satisfied**	Need completely or mostly **unsatisfied**
Care and supervision of the person[39]	☐ 0	☐ 4	☐ 8
Care of the domestic environment[40]	☐ 0	☐ 2	☐ 4
Person's social needs[41]	☐ 0	☐ 2	☐ 4

Total ______ /16

LEVEL OF CARE AND SOCIAL DEFICITS

Convert the total score for FULFILMENT OF CARE AND SOCIAL NEEDS DEFICITS to the score for CARE AND SOCIAL DEFICITS, using this conversion table.

Total score for fulfilment of care and social needs deficits	CARE AND SOCIAL DEFICITS
0 /16	**NULL** ☐ **0**
2–4 /16	**SLIGHT** ☐ **2**
6–8 /16	**MODERATE** ☐ **5**
10–12 /16	**SEVERE** ☐ **8**
14–16 /16	**TOTAL** ☐ **10**

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[39] Needs assistance to carry out Activities of Daily Living, including day/night surveillance.

[40] Needs not strictly linked to the direct care of the person, such as cleaning of living spaces and washing of clothes, etc.

[41] Both in the home and outdoors.

SH/Ar	**ACCESSIBILITY ISSUES ASSESSMENT**	**A3**

ACCESSIBILITY ISSUES when carrying out activities at home

Use this table to assess the level of criticality of the **accessibility issues** <u>**only referred to the physical environment**</u> **encountered by the disabled person (with or without caregiver/s)** when performing certain classes of activities at home.

Classes of activity	**Non-compatible activities**[42]	**LEVEL OF CRITICALITY OF ACCESSIBILITY ISSUES**			**(ACS)**[43]
		None or low	***Medium***	***High***	
1. Reaching/Leaving the home*		☐0	☐1	☐2	
2. Moving inside the home*		☐0	☐1	☐2	
3. Access and enjoyment of the home's outdoor spaces	☐	☐0	☐1	☐2	☐1
4. Eating*		☐0	☐1	☐2	
5. Preparing meals	☐	☐0	☐1	☐2	☐1
6. Carrying out physiological needs*		☐0	☐1	☐2	
7. Personal hygiene*		☐0	☐1	☐2	
8. Sleep/rest*		☐0	☐1	☐2	
9. Getting dressed*		☐0	☐1	☐2	
10. Controlling environmental features	☐	☐0	☐1	☐2	☐1
11. Controlling personal safety	☐	☐0	☐1	☐2	☐1
12. Communicating at a distance	☐	☐0	☐1	☐2	☐1
13. Work, study	☐	☐0	☐1	☐2	☐1
14. Leisure activities	☐	☐0	☐1	☐2	☐1
15. Carrying out domestic chores	☐	☐0	☐1	☐2	☐1
16. Carrying out rehabilitation activities	☐	☐0	☐1	☐2	☐1
17. Other:		☐0	☐1	☐2	☐1
18. Other:		☐0	☐1	☐2	☐1
19. Other:		☐0	☐1	☐2	☐1
20. Other:		☐0	☐1	☐2	☐1

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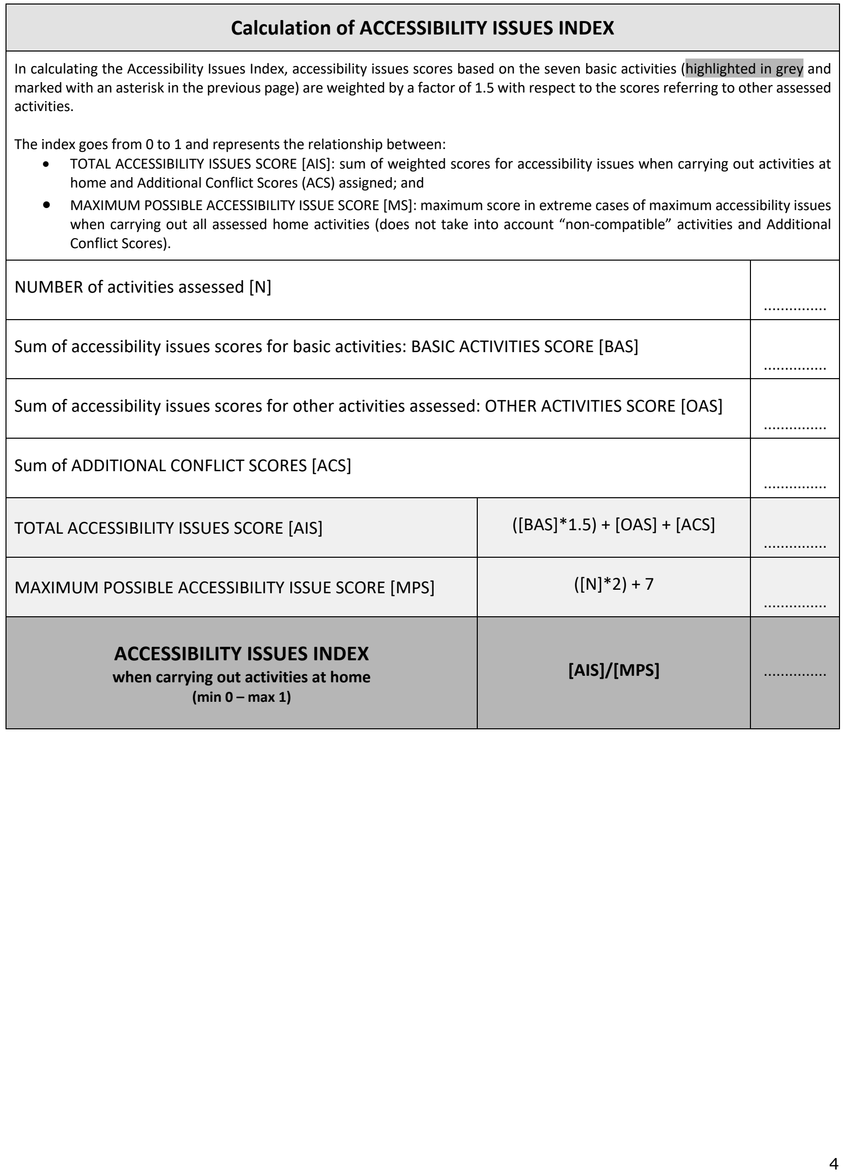
[42] **Non-compatible activities shall NOT be assessed.**

[43] Additional Conflict Scores (ACS) can be assigned when a high critical situation refers to an activity (other than Basic) that is particularly significant to the disabled person (and/or the main caregiver/s).



Calculation of ACCESSIBILITY ISSUES INDEX

In calculating the Accessibility Issues Index, accessibility issues scores based on the seven basic activities (highlighted in grey and marked with an asterisk in the previous page) are weighted by a factor of 1.5 with respect to the scores referring to other assessed activities.

The index goes from 0 to 1 and represents the relationship between:

- TOTAL ACCESSIBILITY ISSUES SCORE [AIS]: sum of weighted scores for accessibility issues when carrying out activities at home and Additional Conflict Scores (ACS) assigned; and
- MAXIMUM POSSIBLE ACCESSIBILITY ISSUE SCORE [MS]: maximum score in extreme cases of maximum accessibility issues when carrying out all assessed home activities (does not take into account "non-compatible" activities and Additional Conflict Scores).

NUMBER of activities assessed [N]		....
Sum of accessibility issues scores for basic activities: BASIC ACTIVITIES SCORE [BAS]		....
Sum of accessibility issues scores for other activities assessed: OTHER ACTIVITIES SCORE [OAS]		....
Sum of ADDITIONAL CONFLICT SCORES [ACS]		....
TOTAL ACCESSIBILITY ISSUES SCORE [AIS]	([BAS]*1.5) + [OAS] + [ACS]	....
MAXIMUM POSSIBLE ACCESSIBILITY ISSUE SCORE [MPS]	([N]*2) + 7	....
ACCESSIBILITY ISSUES INDEX **when carrying out activities at home** **(min 0 – max 1)**	**[AIS]/[MPS]**	....

SH/Ar	**AUTONOMY AT HOME LIMITATION SCORE**	**A4**

To be completed only for grant applicants,
AFTER ALL GRANT APPLICANTS HAVE BEEN ASSESSED

AUTONOMY AT HOME LIMITATION SCORE	
All disabled persons may obtain a maximum of 100 points, in these proportions: • **Limitation of functional autonomy**: max 20 points • **Care and social deficits:** max 10 points • **Accessibility issues**: max 70 points	
	SCORE
1. LIMITATION OF FUNCTIONAL AUTONOMY (max 20 points)	…………… /20
2. CARE AND SOCIAL DEFICITS (max 10 points)	……………/10
3. ACCESSIBILITY ISSUES (max 70 points)	……………/70[44]
AUTONOMY AT HOME LIMITATION SCORE **(max 100 points)**	**……………/100**

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[44] In order to be used for calculating the *Autonomy at Home Limitation Score*, the *Accessibility Issues Index* must be converted from a value of 0 to 1 to a score of 0 to 70. For the conversion, assign a maximum value (70 points) to the individual who obtained the highest *Accessibility Issues Index* score of all those ranked, then re-calculate the values of the other individuals proportionally.
Therefore:
ACCESSIBILITY ISSUES score (max 70 points) = (ACCESSIBILITY ISSUES INDEX score / max score for the ACCESSIBILITY ISSUES INDEX among all ranked participants) * 70.

The Florence Accessibility Lab

The Florence Accessibility Lab (FAL) is an Interdepartmental Research Unit created in 2013 following more than two decades of research activity into environmental accessibility and social inclusion. The main goals of the *Florence Accessibility Lab* are to define, consolidate and promote a new design culture that considers environmental accessibility a great collective resource for human autonomy and well-being in order to make local communities more dynamic, safe and cohesive, exploiting architectural and landscape heritage, as well as for the development of advanced technologies for the person. In short, for "human development", as intended by the United Nation Development Programme. The cultural framework of the Florence Accessibility Lab is based on the central role of the human being in habitat transformation processes and on the need for those processes to be guided by a deep knowledge of socio-economic dynamics and a caring attitude to commons.

The Research Unit adopts an interdisciplinary approach and works in a wide range of applied fields, at various levels, from cultural heritage to tourism, urban security and quality to urban mobility, from objects to street furniture, from housing adaptation to public buildings. The Florence Accessibility Lab also promotes and organises several kinds of advanced education projects (training and refresher courses, workshops, seminars, summer schools, Master's courses, etc.).

Since its creation, the Florence Accessibility Lab has hosted Italian and foreign scholars, PhD candidates and graduate students, all sharing a research interest in accessibility and disability. At the moment, the Research Unit is composed of eighteen professors from the University of Florence, from the departments of Architecture (DIDA), Industrial Engineering (DIEF), Economics and Management (DISEI), Political and Social Sciences (DSPS), and Education and Psychology (SCIFOPSI), and of various other research fellows, contributors and consultants both from Italy and abroad.

Antonio Laurìa, Beatrice Benesperi, Paolo Costa, Fabio Valli, *Designing Autonomy at Home. The ADA Project. An Interdisciplinary Strategy for Adaptation of the Homes of Disabled Persons*, ISBN (online PDF) 978-88-6453-898-3,

The Florence Accessibility Lab was the defining model for other accessibility labs officially created in the Universities of Brescia, Naples (Federico II), Reggio Calabria, and in the Polytechnic University of Turin.

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Italian Law 104/1992 as subsequently amended and supplemented, Legge-quadro per l'assistenza, l'integrazione sociale e i diritti delle persone handicappate. (*Framework law applicable to assistance, social integration and rights of the disabled*)

Italian Ministerial Decree 236/1989, Prescrizioni tecniche necessarie a garantire l'accessibilità, l'adattabilità e la visitabilità degli edifici privati e di edilizia residenziale pubblica sovvenzionata e agevolata, ai fini del superamento e dell'eliminazione delle barriere architettoniche (*Technical provisions for ensuring the accessibility, adaptability and visitability of private buildings and of subsidised public housing intending to overcome and eliminate architectural barriers*).

Tuscany Regional Government Law 66/2008, Istituzione del fondo regionale per la non autosufficienza, as subsequently amended and supplemented (*Establishment of the regional fund for non-self-sufficiency*).

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Antonio Laurìa, Beatrice Benesperi, Paolo Costa, Fabio Valli, *Designing Autonomy at Home. The ADA Project. An Interdisciplinary Strategy for Adaptation of the Homes of Disabled Persons*, ISBN (online PDF) 978-88-6453-898-3,

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