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TECHNICAL REPORT

Human Factors (HF);
Functional needs of people with cognitive disabilities when using mobile ICT devices for an improved user experience in mobile ICT devices

ETSI

650 Route des Lucioles
F-06921 Sophia Antipolis Cedex - FRANCE

Tel.: +33 4 92 94 42 00   Fax: +33 4 93 65 47 16

Siret N° 348 623 562 00017 - NAF 742 C
Association à but non lucratif enregistrée à la
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Foreword

This Technical Report (TR) has been produced by ETSI Technical Committee Human Factors (HF).

Modal verbs terminology

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Introduction and how to use the present document

Individuals with cognitive impairments can benefit significantly with the proper use of ICT mobile devices; however, they can face many challenges when using mobile ICT devices and their applications.

Although there are significant publications (from standardisation bodies as well as from published research) that examine the functional needs of people with physical and sensory impairments on the use of Mobile ICT, there is very limited relevant work on the needs of people with cognitive impairments.

In this respect, the present document aims to describe the functional needs of people with limited cognitive, language and learning abilities in effectively using mobile ICT devices. Research studies and scientific papers along with familiarisation with the cognitive impairments form the basis for identifying relevant usage needs.

The present document contains design guidelines for mobile devices and applications that will enable persons with limited cognitive, language and learning abilities (e.g. people with age-related cognitive impairments) to have an improved user experience when using mobile ICT devices and applications. The usage needs in the present document complement already identified usage needs such as those in documents in the references clause.

The present document supplements ETSI EG 203 350: "Guidelines for the design of mobile ICT devices and their related applications for people with cognitive disabilities" [i.1] that contains design guidelines for mobile devices and applications that will enable persons with cognitive impairments to have an improved user experience when using mobile ICT devices and applications.

1 Scope

The present document contains a classification and analysis of usage needs of persons with limited cognitive, language and learning abilities (generically and historically referred to as "cognitive impairments"). It describes their functional needs for an improved user experience when using mobile ICT devices and applications.

The present document is the basis for the development of design guidelines for mobile ICT devices and applications ETSI EG 203 350: "Human Factors (HF); Guidelines for the design of mobile ICT devices and their related applications for people with cognitive disabilities" [i.1] that enables people with cognitive impairments to obtain the maximum benefit from the use of mobile ICT.

2 References

2.1 Normative references

Normative references are not applicable in the present document.

2.2 Informative references

References are either specific (identified by date of publication and/or edition number or version number) or non-specific. For specific references, only the cited version applies. For non-specific references, the latest version of the referenced document (including any amendments) applies.

NOTE: While any hyperlinks included in this clause were valid at the time of publication, ETSI cannot guarantee their long term validity.

The following referenced documents are not necessary for the application of the present document but they assist the user with regard to a particular subject area.

[i.1] ETSI EG 203 350: "Human Factors (HF); Guidelines for the design of mobile ICT devices and their related applications for people with cognitive disabilities".

[i.2] Alzheimer Disease, National Institute on Aging, Alzheimer's Disease Education and Referral Center.

NOTE: Available at www.nia.nih.gov/alzheimers/publication/alzheimers-disease-fact-sheet.

[i.3] Alzheimer's Association. (2014). 2014 Alzheimer's disease facts and figures. Alzheimer's & Dementia, 10(2), e47-e92.

[i.4] American Psychiatric Association. (2013). Diagnostic and Statistical Manual of Mental Disorders (DSM-5®). American Psychiatric Pub.

[i.5] American Speech-Language-Hearing Association, Aphasia.

NOTE: Available at www.asha.org/PRPSpecificTopic.aspx?folderid=8589934663&section=Incidence_and_Prevalence.

[i.6] American Speech-Language-Hearing Association, Childhood Fluency Disorders.

NOTE: Available at http://www.asha.org/PRPSpecificTopic.aspx?folderid=8589935336&section=Incidence_and_Prevalence.

[i.7] American Speech-Language-Hearing Association, Social Communication Disorders in School - Age Children.

NOTE: Available at http://www.asha.org/PRPSpecificTopic.aspx?folderid=8589934980&section=Incidence_and_Prevalence.

[i.8]   American Speech-Language-Hearing Association: Speech Sound Disorders-Articulation and Phonology.

NOTE: Available at http://www.asha.org/PRPSpecificTopic.aspx?folderid=8589935321&section=Incidence_and_Prevalence.

[i.9]   Braddock, D.; Rizzolo, M.; Thompson, M.; Bell, R. Emerging Technologies and Cognitive Disability. Journal of Special Education Technology, 19 (4), 2004. pp. 49-56.

[i.10]   Bölte, S., de Schipper, E., Robison, J. E., Wong, V. C.N., Selb, M., Singhal, N., de Vries, P. J. and Zwaigenbaum, L. (2014), Classification of Functioning and Impairment: The Development of ICF Core Sets for Autism Spectrum Disorder. Autism Res, 7: 167-172. doi: 10.1002/aur.1335.

[i.11]   Burke, M. (2013). Development of a core set for aphasia using the International Classification of Functioning, Disability and Health (ICF) (Order No. 1541098). Available from ProQuest Dissertations & Theses Global. (1418261949). Retrieved from http://search.proquest.com/docview/1418261949?accountid=15299.

[i.12]   de Schipper, E., Lundequist, A., Coghill, D., de Vries, P. J., Granlund, M., Holtmann, M., Jonsson, U., Karande, S., Robison, J. E., Shulman, C., Singhal, N., Tonge, B., Wong, V. C.N., Zwaigenbaum, L. and Bölte, S. (2015), Ability and Disability in Autism Spectrum Disorder: A Systematic Literature Review Employing the International Classification of Functioning, Disability and Health-Children and Youth Version. Autism Res. doi: 10.1002/aur.1485.

[i.13]   ETSI EN 301 549: "Accessibility requirements suitable for public procurement of ICT products and services in Europe".

[i.14]   ETSI EG 201 013: "Human Factors (HF); Definitions, abbreviations and symbols".

[i.15]   Gan, S. M., Tung, L. C., Yeh, C. H., Chang, H. Y., & Wang, C. H. (2013). The ICF-CY-based structural equation model of factors associated with participation in children with autism. Developmental neurorehabilitation, 17(1), 24-33.

[i.16]   Gan, S. M., Tung, L. C., Yeh, C. Y., & Wang, C. H. (2013). ICF-CY based assessment tool for children with autism. Disability and rehabilitation, 35(8), 678-685.

[i.17]   International Statistical Classification of Diseases and Related Health Problems 10th Revision - ICD-10 Version:2016.

NOTE: Available at http://apps.who.int/classifications/icd10/browse/2016/en.

[i.18]   International Dyslexia Association, Dyslexia Basics.

NOTE: Available at http://eida.org/dyslexia-basics/.

[i.19]   ISO/IEC TR 29138-1:2009 "Information technology - Accessibility considerations for people with disabilities -Part 1:User needs summary".

[i.20]   Mayo Clinic, Diseases and Conditions, Down Syndrome.

NOTE: Available at www.mayoclinic.org/diseases-conditions/down-syndrome/basics/symptoms/con-20020948.

[i.21]   McCormack, J., & Worrall, L. E. (2008). The ICF Body Functions and Structures related to speech-language pathology. International journal of speech-language pathology, 10(1-2), 9-17.

[i.22]   National Institute of Neurological Disorders and Stroke, Autism Spectrum Disorder fact sheet.

NOTE: Available at www.ninds.nih.gov/disorders/autism/detail_autism.htm.

[i.23]   National Resource Center on AD HD, "About ADHD".

NOTE: Available at http://www.chadd.org/Understanding-ADHD/About-ADHD.aspx.

[i.24]   OECD Centre for Educational Research and Innovation - CERI - Dyscalculia Primer and Resource Guide.

NOTE: Available at http://www.oecd.org/edu/ceri/dyscalculiaprimerandresourceguide.htm.

[i.25]   Riva, S., Antonietti, A., The Application of the ICF Model in specific learning difficulties: A Case Study, Psychology of Language and Communication 2010, Vol. 14 No. 2, pp. 37-58.

[i.26]   Rowland, C., Fried-Oken, M., Steiner, S. A., Lollar, D., Phelps, R., Simeonsson, R. J., & Granlund, M. (2012). Developing the ICF-CY for AAC profile and code set for children who rely on AAC. Augmentative and Alternative Communication, 28(1), 21-32.

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[i.28]   Söderström, S., Pettersson, R., Edlund-Söderström, K., Ganse, G., Holmkvist, E., Westin, O., & Haglund, L. (2014). Development of a Swedish Comprehensive International Classification of Functioning, Disability and Health (ICF) Core Set for adult patients with attention-deficit hyperactivity disorder (ADHD). Nordic journal of psychiatry, 68(3), 161-168.

[i.29]   U.S. Department of Health & Human Services National Institutes of Health National Institute on Deafness and other Communicatin Disorders, Fact Sheet Aphasia.

NOTE: Available at https://www.nidcd.nih.gov/sites/default/files/Documents/health/voice/Aphasia6-1-16.pdf.

[i.30]   WHO Fact sheet Nr. 362, March 2015, Dementia.

NOTE: Available at www.who.int/mediacentre/factsheets/fs362/en/.

[i.31]   WHO Genes and Chromosomal diseases, Down Syndrome.

NOTE: Available at www.who.int/genomics/public/geneticdiseases/en/index1.html.

[i.32]   World Health Organization. (2007). International classification of functioning, disability and health: children & youth version: ICF-CY. World Health Organization.

[i.33]   Intellectual Disability Factsheet, The American Psychiatric Association, APA 2013.

[i.34]   American Association of Intellectual and Developmental Disabilities: "Definition of Intellectual Disability".

NOTE: Available at https://aaidd.org/intellectual-disability/definition#.V0tZvpN97Ur.

[i.35]   World Health Organization (2001). The World Health Report 2001 - Mental Health: New Understanding, New Hope. Geneva: 178 pp.

[i.36]   Special Olympics - Policy Paper, Health, Well-Being and Opportunity for people with Intellectual Disability, Global Imperative, "Status and Prospects of Persons with Intellectual Disability.

NOTE: Available at http://www.specialolympics.org/uploadedFiles/LandingPage/WhatWeDo/Research_Studies_Desciption_Pages/Policy_Paper_Status_Prospects.pdf.

[i.37]   What's the Difference Between a Speech Impairment and a Language Disorder by Ellen Koslo.

NOTE: Available at https://www.understood.org/en/learning-attention-issues/child-learning-disabilities/communication-disorders/difference-between-speech-impairment-and-language-disorder.

[i.38]   Maja Nørgård Jacobsen M.Sc., Carolyn Ha M.A. & Carla Sharp Ph.D. (2015) A Mentalization-Based Treatment Approach to Caring for Youth in Foster Care, Journal of Infant, Child, and Adolescent Psychotherapy, 14:4, 440-454, DOI: 10.1080/15289168.2015.1093921.

NOTE: Available at http://dx.doi.org/10.1080/15289168.2015.1093921.

[i.39]   The Next Big Thing In Design? Less Choice.

NOTE: Available at https://www.fastcodesign.com/3045039/the-next-big-thing-in-design-fewer-choices.

3   Definitions and abbreviations

3.1   Definitions

For the purposes of the present document, the terms and definitions given in ETSI EG 201 013 [i.14] and the following apply:

activity: execution of a task or action by an individual

NOTE: Sources: [i.35].

activity limitation: difficulty an individual may have in executing an activity

NOTE: Sources: [i.35].

body function: physiological function of body systems (including psychological systems)

NOTE: Sources: [i.35].

cognitive disability: activity limitations or participation restrictions that occur when factors in the environment contain barriers for persons with cognitive impairments

cognitive impairment: substantial limitation in person's capacity to think, including conceptualizing, planning, and sequencing thoughts and actions, remembering, interpreting subtle social cues, and understanding numbers and symbols

NOTE: Sources: [i.9].

Information and Communication Technology (ICT): technology, equipment, or interconnected system or subsystem of equipment for which the principal function is the creation, conversion, duplication, automatic acquisition, storage, analysis, evaluation, manipulation, management, movement, control, display, switching, interchange, transmission, reception, or broadcast of data or information

NOTE: Examples of ICT are electronic content, telecommunications products, computers and ancillary equipment, software, information kiosks and transaction machines, videos, IT services, and multifunction office machines which copy, scan, and fax documents.

mobile ICT: ICT that uses mobile technologies

NOTE: Mobile technologies include, but are not limited to, mobile phones, smartphones, tablets, smart watches and services accessed through these devices.

participation restriction: problem an individual may have in involvement in life situations

NOTE: Sources: [i.35].

usage need: specific support needed by an individual to overcome an activity limitation

NOTE 1:   Defining usage needs from activities allows a "design for all" approach to be followed, as the usage needs are based on supporting users doing activities they have trouble with (reading, speaking, organising, etc.) without the need to consider the reasons (the impairments or diagnoses) for those limitations.

NOTE 2:   The usage needs in the present document are those that are relevant when individuals are interacting with mobile ICT.

3.2   Abbreviations

For the purposes of the present document, the following abbreviations apply:

ADHD   Attention-Deficit/Hyperactivity Disorder
APA   American Psychiatric Association
ASD   Autism Spectrum Disorder
DfA   Design for All
DSM   Diagnostic and Statistical Manual

ICD   International Classification of Diseases
ICD-10   International Classification of Diseases 10th Revision
ICF   International Classification of Functioning, Disability and Health
ICF-CY   International Classification of Functioning, Disability and Health for Children and Youth
ICT   Information and Communication Technology
LD   Learning Disability
MCI   Mild Cognitive Impairment
WHO   World Health Organization

4 Background and approach

The present document uses a standards-based approach for defining cognitive impairments and usage needs.

Two major sources of information have been used for identifying the major cognitive impairments: the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) [i.17], from the World Health Organization (WHO) and the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) [i.4] from the American Psychiatric Association (APA). Both documents include information about cognitive impairments, as part of a wider collection of mental and behavioural disorders and impairments.

The first step involved the definition and selection of a subset of cognitive impairments based on scientific literature and on two criteria. The first criterion is **prevalence**, that is, how many individuals have a particular cognitive impairment. The second one is **potential use and benefits**, that is, whether persons having a particular cognitive impairment can use mobile technologies, with the support of the required assistive technologies. Based on this approach, the following cognitive impairments have been defined and selected:

- Dementia and Alzheimer's disease

- Intellectual impairments including Down syndrome

- Aphasia

- Speech and Language Impairments

- Autism

- Attention-Deficit/Hyperactivity Disorder - ADHD

- Dyslexia

- Dyscalculia

The second step was to relate and describe further the identified cognitive impairments mainly based on the activities (execution of tasks or actions by an individual) and if necessary - but also limited - on body functions (physiological functions of body systems, including psychological ones) by using the vocabulary of the WHO ICF-CY, the International classification of functioning, disability and health, children and youth version [i.35].

A broad range of ICF activities and functions was derived from the cognitive impairments listed above. However, it is not only persons who have these cognitive impairments that experience limitations in relation to these activities or impairments in the functions. Similar limitations and impairments may be experienced by most people in situations of high stress or cognitive overload (e.g. when attempting to multi-task). This means that any guidelines derived from the usage needs described in the present document are likely to be of benefit to a much wider range of people and situations than those directly associated with the cognitive impairments and diagnoses listed above.

The third step was to define a new set of usage needs that are based on the related ICF activities and in some cases also on ICF functions. The outcomes from this step are described in clause 6.

NOTE 1: Defining usage needs from activities allows a "design for all" approach to be followed, as the usage needs are based on supporting users doing activities they have trouble with (reading, speaking, organising, etc.) without the need to consider the reasons (the impairments or diagnoses) for those limitations.

NOTE 2: The approach applied in the present document is to identify activities that are relevant when individuals are interacting with mobile ICT, and then to define usage needs for those activities.

NOTE 3: In some cases, it may be necessary to refer in addition to ICF functions, either because there is no relevant ICF activity (as it is the case with memory) or because the functions can provide additional details to activities (as is the case with attention).

NOTE 4: Each usage need has a unique identifier to enable cross-referencing.

5   Cognitive impairments and diagnoses

5.1   Introduction

Clause 5 outlines the nine selected cognitive impairments that fall within the scope of the present document and resulted mainly from the first two steps in the approach. Each relevant cognitive impairment is outlined in a table in a form of a "fact sheet".

5.2   Dementia and Alzheimer fact sheet

Table 1: Dementia and Alzheimer's disease fact sheet

Name of disorder	Dementia and Alzheimer's disease
DSM-5 Classification [i.4]	**Dementia:** Neurodevelopmental Disorders (31)/Intellectual Disabilities (33) **Alzheimer's disease:** Neurocognitive Disorders (591)/ Major or Mild Neurocognitive Disorder Due to Alzheimer's disease (611)
ICD-10 Classification [i.17]	**Dementia:** • F00 Dementia in Alzheimer disease • F01 Vascular Dementia • F02 Dementia in other diseases classified elsewhere • F03 Unspecified dementia **Alzheimer's disease:** • G30 Alzheimer disease
Description	**Dementia:** Dementia is a syndrome in which there is deterioration in memory, thinking, behaviour and the ability to perform everyday activities. Although dementia mainly affects older people, it is not a normal part of ageing. Alzheimer's disease is the most common cause of dementia and may contribute to 60 - 70 % of cases. Dementia is one of the major causes of disability and dependency among older people worldwide. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment. Consciousness is not affected. Dementia is caused by a variety of diseases and injuries that primarily or secondarily affect the brain, such as Alzheimer's disease or stroke. It is one of the major causes of disability and dependency among older people worldwide. It is overwhelming not only for the people who have it, but also for their caregivers and families. Sources: [i.30]
Diagnosis/Main symptoms	**Dementia Signs and symptoms:** The symptoms linked to dementia can be understood in three stages. Early stage: forgetfulness, losing track of the time, becoming lost in familiar places. Middle stage: becoming forgetful of recent events and people's names, becoming lost at home, having increasing difficulty with communication, needing help with personal care, experiencing behaviour changes, including wandering and repeated questioning. Late stage: becoming unaware of the time and place, having difficulty recognizing relatives and friends, having an increasing need for assisted self-care, having difficulty walking, experiencing behaviour changes that may escalate and include aggression.

Name of disorder	Dementia and Alzheimer's disease
	Common forms: Alzheimer's disease is the most common form of dementia and may contribute to 60 % - 70 % of cases Sources: [i.30] **Alzheimer's disease signs and symptoms:** First symptoms For many, decline in non-memory aspects of cognition, such as word-finding, vision/spatial issues, and impaired reasoning or judgment, may signal the very early stages of Alzheimer's disease. **Mild Alzheimer's disease:** As Alzheimer's disease progresses, people experience greater memory loss and other cognitive difficulties. Problems can include wandering and getting lost, trouble handling money and paying bills, repeating questions, taking longer to complete normal daily tasks, and personality and behaviour changes. **Moderate Alzheimer's disease:** Memory loss and confusion grow worse, and people begin to have problems recognizing family and friends. They may be unable to learn new things, carry out multistep tasks such as getting dressed, or cope with new situations. In addition, people at this stage may have hallucinations, delusions and paranoia, and may behave impulsively. **Severe Alzheimer's disease:** People with severe Alzheimer's cannot communicate and are completely dependent on others for their care. Sources: [i.2] and [i.3]
Prevalence- How many people are affected?	**Dementia:** Worldwide, 47,5 million people have dementia and there are 7,7 million new cases every year, with just over half (58 %) living in low- and middle-income countries. Every year, there are 7,7 million new cases. The estimated proportion of the general population aged 60 and over with dementia at a given time is between 5 to 8 per 100 people. The total number of people with dementia is projected to 75,6 million in 2030 and almost triple by 2050 to 135,5 million. Sources: [i.30]. **Alzheimer's disease:** The prevalence of overall dementia rises steeply with age. In high-income countries, it ranges from 5 % to 10 % in the seventh decade to at least 25 % thereafter. The percentage of dementias attributable to Alzheimer's disease ranges from about 60 % to over 90 %, depending on the setting and diagnostic criteria. Mild dementia due to Alzheimer's disease is likely to represent a substantial fraction of Mild Cognitive Impairment (MCI) as well. Sources: [i.2] and [i.3]
Potential use and benefits	**Dementia and Alzheimer's disease:** If in a late phase of the disease, people become too unfocused and forgetful, they may not be able to actively use mobile technology or take in information presented from an electronic device. They may, however, benefit indirectly from the passive use of such devices, e.g. for location and communication purposes (help button, "baby phone" functionality). In all phases of the disease, people benefit from using mobile technologies, e.g. for reminding them of regular or special events or for leading them home if they get lost. Mobile technology may also support caregivers.

Name of disorder	Dementia and Alzheimer's disease
Related ICF Activities and Participation, Sources: [i.35] and [i.26]	**Learning and Applying Knowledge:** d110 Watching, d115 Listening, d130 Copying, d135 Rehearsing, d1550 Acquiring basic skills, d1551 Acquiring complex skills,d160 Focusing attention, d163 Thinking, d166 Reading, d170 Writing, d172 Calculating, d175 Solving Problems, d1750 Solving simple problems, d1751 Solving complex problems, d177 Making decisions. **General Tasks and Demands:** d210 Undertaking a single task, d2100 Undertaking a simple task, d2101 Undertaking a complex task, d2102 Undertaking a single task independently, d2103 Undertaking a single task in a group, d220 Undertaking multiple tasks, d2200 Carrying out multiple tasks, d2201 Completing multiple tasks, d2202 Undertaking multiple tasks independently, d2203 Undertaking multiple tasks in a group, d230 Carrying out daily routine, d2301 Managing daily routine, d2302 Completing the daily routine, d2303 Managing one's own activity level. **Communication:** d310 Communicating with - receiving - spoken messages, d315 Communicating with - receiving - nonverbal messages, d3150 Communicating with - receiving - body gestures, d3151 Communicating with - receiving - general signs and symbols, d3152 Communicating with - receiving - drawings and photographs, d325 Communicating with - receiving - written messages, d330 Speaking, d335 Producing nonverbal messages, d3350 Producing body language, d3351 Producing signs and symbols, d3352 Producing drawings and photographs, d345 Writing messages, d3500 Starting a conversation, d3501 Sustaining a conversation, d3502 Ending a conversation, d3503 Conversing with one person, d3504 Conversing with many people, d355 Discussion, d3550 Discussion with one person, d3551 Discussion with many people, d360 Using communication devices and techniques. **Mobility:** d440 Fine hand use (picking up, grasping).
Additional ICF Body Functions for complimenting ICF Activities. Sources: [i.35] and [i.27]	**Mental Functions:** b140 Attention functions, b1400 Sustaining attention, b1401 Shifting attention, b1402 Dividing attention, b144 Memory functions, b1440 Short-term memory, b1441 Long-term memory, b1442 Retrieval of memory.
NOTE:	The description of dementia says that it involves problems in almost all cognitive functions: memory, language, thinking, orientation, calculating, communicating, etc. For this reason the list of ICF items related to dementia includes so many functions and activities.