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Easy to understand communication during COVID in Hungary

The legal institution of supported decision-making was introduced by the Civil Code in force on 15 March 2014, in addition to the CLV of 2013 on supported decision-making. The Act regulates the provisions on the appointment of a support worker, the duties of a support worker or a professional support worker and the records keeping. The supported decision-making system helps to make decisions based on individual needs without restricting the capacity to act.

In the new COVID epidemic situation, the supported decision-making for people with intellectual disabilities is temporarily difficult. The National Public Health Center issued a leaflet on March 10, 2020. The information changed rapidly, the rules were constantly expanding. In the current situation, equal access to the necessary information for supported decision-making was not available in a uniform format.

The examples show that professionals and NGOs dealing with easy-to-understand communication responded almost immediately to the situation and provided information about the health emergency. In 2020, more practices developed in the civil and institutional sectors, the impact of which is still being felt today. In addition to easy-to-understand content translations and self-contained information materials, communication-friendly content has also been developed for healthcare professionals.

In this study, I present the COVID information published in easy-to-understand communication in chronological order. An overview of these can support the development of unified strategic steps in a subsequent emergency situation.

Keywords: easy-to-understand communication, COVID

INTRODUCTION

The period of the COVID health emergency fundamentally changed people's way of life and their habits. The changes took place within days and had to be adapted to quickly. One of the pillars of successful adaptation was information that made it easy to understand the situation, the rules that had to be adapted and the conditions that had to be met. The information was made available through a variety of communication channels, which were presented in different language versions. The main source of information is the legislation governing the management of health emergencies, although for the majority of society this content is difficult to understand due to technical terminology. For this reason, news channels have provided the general public with a clear overview of the basic regulations, and have also taken over from each other the information translated into the vernacular. The centralised information source was created on 1 March 2020 (<https://koronavirus.gov.hu/cikkek/magyarorszagon-nincs-korlatozas-0>) and the associated community site was created on 27 February 2020 and launched on 4 March 2020 (https://m.facebook.com/photo/?fbid=102334918043405&set=a.189344896716631&_rdr) where all interested parties could find uniform information in a transparent format. In addition, the Government has provided information to the public with a unified image, identifiable media faces and a single news portal. For poster campaigns and media appearances, a simple level of language close to or equivalent to easy-to-

understand communication was often used to reach a wider audience, but not for longer information content.

TECHNICAL LANGUAGE AND COMMON LANGUAGE IN THE REGULATION OF HEALTH EMERGENCIES

The first piece of legislation was the Government Decree 40/2020 (11 March) on the Declaration of a State of Emergency, which was published in the Hungarian Gazette, Issue 39 of 11 March 2020. The Government Decree declared a state of emergency for the entire territory of Hungary. In addition, as a basic measure to safeguard the health and lives of Hungarian citizens, it conferred decision-making powers on the Prime Minister and established the Operational Group Responsible for Protection Against the Coronavirus Epidemic. Extraordinary measures to deal with the state of emergency were laid down in separate government decrees. As of 16 March 2020, the decrees regulated the organisation of education in schools in a digital work schedule outside the classroom (Hungarian Gazette, Issue 42, 1382, 1388), banned events and allowed restaurants and cafés to stay open until 15:00.

All of these regulations, drafted in the above-mentioned technical language to prepare service providers or institutions, have also affected the daily lives of different groups of people with intellectual disabilities. The up-to-date information extracted from the legislation on health emergencies and their management was presented to the public in a concentrated way on the central news portal (www.koronavirus.gov.hu) and in various media outlets.

The majority of Hungarian citizens interpreted the rules, assessed them and respected them, taking into account the consequences. However, the health emergency brought important changes for everyone, which went beyond the comfort zone of the individuals. Accordingly, persons with intellectual disabilities perceived the change with different decision-making capacities in different institutional settings. The people in their lives informed them of the rules to be followed according to their communication needs. However, with the development of *plain language information for society*, there was no uniformly communicated information content to support equal access to information.

LEGAL INSTITUTIONAL SYSTEMS FOR DECISION-MAKING AND THEIR RELATION TO HEALTH EMERGENCIES

Different legal institutions for decision-making have played various roles in understanding the rules in relation to health emergencies. This study reviews successful information from the perspective of people with intellectual disabilities. In the field of decision-making, two different situations could arise. In the system of substitute decision-making, the priority was to understand the change that occurred,

to accept the rules and to comply with them, while for some groups of cases of limited capacity and in cases assigned to the system of supported decision-making, the priority was to make life decisions related to the new situation, for which there had not been any previous opportunity for practice and learning during the state of emergency. A more detailed overview of the two types of decision situations justifies the need to use easy-to-understand communication.

1) An adult person with discernment can make an independent decision about whether to follow a rule in a health emergency. In addition, in the legal institution of limited capacity in respect of a group of cases, they can make an autonomous decision concerning the epidemic control regulations. In the legal institution of supported decision-making, introduced by the Civil Code in force on 15 March 2014, it facilitates decision-making on the basis of individual needs without limiting capacity. The operation of the legal system is governed by Act CLV of 2013 on Supported Decision-Making. For example, it sets out the conditions for the appointment of a support worker, the tasks of the support worker or professional support worker, and the keeping of records. In the case of supported decision-making, a person who supports the person's autonomous decision-making provides the necessary information through a channel of communication appropriate to the person.

2) The person cannot make an autonomous decision regarding compliance with the rules relating to the health emergency in the absence of capacity pursuant to Act XV of 2001 on the Amendment of Certain Acts Regarding Legal Capacity and Guardianship. In the case of an adult person without capacity to decide, the legal institution of substitute decision-making comes into force when the decision is taken over by a guardian.

The various decision-making instruments *require both an understanding of the rules that apply to the person concerned, acceptance of the rules and non-compliance with a rule that significantly hinders their life situation* (e.g. abolition of the compulsory wearing of a mask for people with intellectual disabilities). In addition to accepting the rules, supported decision making, limited capacity and incapacity also require making decisions about the changes to their own lives that they affect.

THE STATUS OF EASY-TO-UNDERSTAND COMMUNICATION IN STATES OF EMERGENCY IN HUNGARY

The first publication on easy-to-understand communication was published in 2002 under the title "Simply, Understandably", translated by Zsuzsa Csató and published by the National Association for People Living with Intellectual Disabilities and their Helpers, then known as the Hungarian Association for Persons with Intellectual Disability (Hungarian abbreviation: 'ÉFOÉSZ') (Farkasné Gönczi & Gráf-Jaksa, 2009). The brochure emphasises to whom and for what purpose the easy-to-understand communication should be used and gives guidance on how to use it. ÉFOÉSZ participated in the Pathways 2 project between 2011-13, where they translated the guide "Information for all", developed in 2009 within the framework of the Pathways 1 project "Pathways in adult education for people with intellectual

disabilities”, published in 2012 [The publication date is not included in the publication. The year of publication was determined by the online interface of the National Bibliography of Hungary (<https://www.oszk.hu/mnbwww/K/1707/S.HTML#3233>).], into Hungarian and disseminated it in Hungary (Farkasné Gönczi, 2018). ÉFOÉSZ has continuously applied and still applies the easy-to-understand communication. Thanks to their work, both their website and their social networking platform have a continuous high readership number.

Following ÉFOÉSZ, several organisations and institutions dealing with people with intellectual disabilities have been involved in the field of easy-to-understand communication, recognising its importance and applicability. The range of content produced with easy-to-understand communication has been steadily expanding. The Down Foundation has produced downloadable guides with easy to understand communication marked EUC (Hungarian abbreviation: ‘KÉR’) (<https://www.downalapitvany.hu/node/337>).

On 20 July 2011, Farkasné Rita Gönczi launched the online blog “Easy-to-Understand Kitchen”, which features recipes for cooking with easy-to-understand communication. In 2017, she moved the blog platform to a complex website platform called “Easy-to-Understand Communication – Easy-to-Understand Life” and expanded it with professional content on easy-to-understand communication. The concept and language levels of easy-to-understand communication, developed together with experts in the field, were first published here and have been available in English since 2018 (<https://konnyenertheto.gonczirita.hu/english/definition-easy-to-understand/>). The online format has made it possible to integrate the constantly updated information in the field in one place, making it a source of courses and professional products. On 4 June 2021, at the initiative of Farkasné dr. Rita Gönczi, the website community organised the first international professional conference in Hungary, together with the ELTE Bárczi Gusztáv Faculty of Special Needs Education. In the conference’s collection of papers titled “Easy-to-understand communication, equal access”, a professional definition is now available, enriched with linguistic knowledge. [Access link for the volume: https://edit.elte.hu/Könnyen_érthető_kommunikáció_egyenlő_esélyű_hozzáférés_Nemzetközi_szakmai_konferencia_2021_tanulmánykötete]

“Easy-to-understand communication is the display of *information content elements* in the common language or at a more complex linguistic level, or the development of *independent information content* in a *simple and clear form* that aids the understanding of the information (Farkasné Rita Gönczi here on the website, 2017, id. 2018, modified 2021/a). Easy-to-understand communication is *communication* that uses *linguistic and non-linguistic symbols* in many cases *according to specific rules*. Easy-to-understand communication uses each language’s own linguistic and non-linguistic symbols in the elaboration and delivery of the message. Specific application means that the degree of understanding of the text by the participants in the communication determines the level of easy-to-understand communication used, and adapts the range of grammar and other rules that can be applied accordingly. Participants in easy-to-understand communication consciously or spontaneously apply the rules of message formation in a communication situation” (Farkasné Gönczi, 2021/b). The publications prepared with easy-to-understand communication show that the grammatical rules of the language used are adapted to the linguistic

and non-linguistic rules of easy-to-understand communication and are also adopted with minor changes according to their target group. For example, the frequency of use of pronouns varies in the publications of organizations dealing with intellectually disabled persons representing different language levels. In her 2021 study, Borbála Keszei found the fewest pronouns (3.5% and 3.9%) in the publications of the FSZK, and the most in ÉFOÉSZ publications (6.5% and 9.8%) (Keszei, 2021).

In addition to the formulation of the definition, the emergence of research exploring the applicability of linguistic and non-linguistic symbols is significant. For example, based on a small sample survey published for the first time in 2019 in Hungary, the use of rules related to font size and shape, and background in easy-to-understand communication is not necessary in the sample studied (Farkasné Gönczi et al., 2019). According to research from Zita Vecseri published in the professional-scientific journal *Disability and Society* in 2021, the majority of written content follows the rules for the application of easy-to-understand communication. For instance, a study assessing the sentence length rule shows that in 4 publications, 1,041 sentences were found to be short, while 276 sentences were long (Vecseri, 2021). Based on the research presented above, it can be said that the rules of written or oral application of easy-to-understand communication can be framed, determined in each case by the linguistic competence, passive and active vocabulary of the target person or group.

The online platforms of professionals and organisations already involved in the use of easy-to-understand communication, as well as the national research (for example Farkasné Gönczi et al., 2019; Keszei, 2021; Vecseri, 2021) published from 2019 onwards, have made it possible to use easy-to-understand communication as a relevant tool for equal access to information on centralised health emergencies, and to use the already known communication channels to reach the target group.

THE EMERGENCE OF EASY TO UNDERSTAND COMMUNICATION DURING THE HEALTH EMERGENCY

At the beginning of the health emergency, there was no unified form of equal access to information for people with low language competence who were able to act or had limited capacity to act, or to information for supported decision-making, within the decision-making legal system. The public sector was not yet prepared to apply solutions that respond to different communication needs. Their role was taken over by professionals, NGOs and institutions involved in easy-to-understand communication, responding almost immediately to the situation and providing information on the health emergency.

ONLINE APPEARANCE OF EASY-TO-UNDERSTAND COMMUNICATION IN THE CASE OF 5 NGOs AND 1 EXPERT

I looked at the timing, spread and topics of the online presence of easy-to-understand communication during the health emergency for 4 national organisations working with people with intellectual disabilities, 1 national organisation working with people with autism spectrum disorders and a community platform linked to my own professional website. I compared and analysed the presentation of information in easy-to-understand communication, the primary topics and the number of shares.

During the communication of the state of emergency, the first easy-to-understand communication information was published on 15 March 2020 on <http://konnyenertheto.gonczirita.hu/2020/03/15/koronavirusrol-konnyen-ertheto-kommunikacioval/>, which was visited by 2,123 people on that day, and by 5,020 in total. The first set of information included a short introduction of the coronavirus, its effects, how it spreads, how to prevent it and what to do in case of infection. At the end of the post, important contact details and authoritative sources of information were provided. The post, which was redirected to social media, was shared by 169 individuals and organisations. Two days later, on 17 March 2020, the <http://konnyenertheto.gonczirita.hu/2020/03/17/szabalyok-a-koronavirus-fertozes-megelozesehez-konnyen-ertheto-kommunikacioval/> post was updated to include information on stay-at-home rules and alternative ways to contact people, which represents 1,615 visits to my website and 55 shares on the social platform. The post also included downloadable information, which could be printed and read offline. The focus of my second set of information was to present the possibilities of communication, because for people who use easy-to-understand communication, the usual channels of communication quickly closed. Developing new analogies to communicate with familiar contacts may have been problematic because of the potential difficulty of thinking in new ways.

On 18 March 2020, ÉFOÉSZ published on their website (<https://efoesz.hu/aktualis-esemenyek/koronavirus-konnyen-ertheto-tajekoztato/>) and on their social media platform, in the form of a poster with 7 shares, key information on the coronavirus, infection and prevention, which could be easily downloaded and displayed. From the next day onwards, several posts per week were produced on the topic until 30 June 2020, making it a safe source of information to monitor and communicate the changing rules.

On 18 April 2020, the Down Foundation added informative content on their website about the coronavirus, how to test for symptoms, prevention and the necessary actions to take (<https://www.downalapitvany.hu/sites/default/files/K%C3%89R%20T%C3%A1j%C3%A9koztat%C3%B3%20a%20Covid%2019%20v%C3%ADrus%C3%B3l.pdf>). It later opened a dedicated section titled “COVID-19” to publish their own content on the subject. The uniqueness of Down Foundation’s online communication is that it runs a news-like video series, which has already been able to reach more people with information about health emergencies because of its visibility.

The Hungarian Autistic Society (Hungarian abbreviation: ‘AOSZ’) informed their members about the activities of their professional network related to the

coronavirus in the early days of the coronavirus on 12 March 2020, and announced their downloadable easy-to-understand content on 21 March 2020 (Kővári, 2020). A specially-created website interface (www.aosz.hu/koronavirus) offers a collection of information sheets, visual aids and AAC tables for download. The website is colour-coded to provide an easy-to-read information base, compiled by the AOSZ professional network. A similar collection portal was developed by the Hand in Hand Foundation on 24 March 2020. Prior to this, they had already been regularly sharing the easy-to-understand content presented above on their social platform since 16 March 2020. The Equal Opportunities of Persons with Disabilities Non-profit Ltd. (Hungarian abbreviation: 'NFSZK') was the first public administration to launch an equal access database on the coronavirus on their website on 16 April 2020.

TABLE 1 AVAILABILITY OF EASY-TO-UNDERSTAND INFORMATION ON THE CORONAVIRUS ON THE FACEBOOK PAGES OF 5 NATIONAL NGOs AND 1 PROFESSIONAL WEBSITE

Date of publication	Author	Shares	Feedback (emoji)	Main content elements	Availability
15.03.2020	Farkansé dr. Rita Gönczi (FGR)	169	25	Communicating about the coronavirus in an easy-to-understand way: definition, impact, spread, prevention	https://tinyurl.hu/k8cd
15.03.2020	ÉTA	3	4	FGR sharing content about the coronavirus through easy-to-understand communication	https://tinyurl.hu/1sBI
16.03.2020	Hand in Hand Foundation	19	16	FGR sharing content about the coronavirus through easy-to-understand communication	https://tinyurl.hu/92Yq
17.03.2020	FGR	55	14	Staying at home, method of contact, rules, downloadable information	https://tinyurl.hu/el0g
18.03.2020	ÉFOÉSZ	35	30	Poster: concept, prevention	https://tinyurl.hu/JkKQ
18.03.2020	FGR	1	1	ÉFOÉSZ poster	www.facebook.com/konynertheto.gonczirita.hu/posts/2954722787899703
19.03.2020	ÉFOÉSZ	30	25	Concept, symptoms, rules, protection, loan moratorium	https://tinyurl.hu/EQoy
19.03.2020	FGR	44	6	Guide at the request of parents: ideas for maintaining contact in residential institutions	https://tinyurl.hu/5vwN
20.03.2020	ÉFOÉSZ	17	16	Concept, symptoms, quarantine, protection, pollution reduction	https://tinyurl.hu/BD6g
21.03.2020	FGR	20	10	Downloadable guide	www.facebook.com/konynertheto.gonczirita.hu/posts/2961026050602710
21.03.2020	AOSZ	314	107	Information from the uniform communication site	https://tinyurl.hu/4tTf
22.03.2020	FGR	4	6	Sharing of handwashing video	www.facebook.com/konynertheto.gonczirita.hu/posts/2964263816945600
23.03.2020	ÉFOÉSZ	14	6	Concept, symptoms, spread, protection, staying at home, protecting the elderly, curfew	https://tinyurl.hu/LWDM
23.03.2020	FGR	15	7	Sharing of ÉFOÉSZ symptom information	https://tinyurl.hu/gOo1
24.03.2020	ÉFOÉSZ	7	11	Concept, staying at home, eviction ban, loan moratorium, international information, cancellation of events, protection	https://tinyurl.hu/L5Th

24.03.2020	ÉFOÉSZ	8	11	Psychological counselling service	https://tinyurl.hu/zMOr
25.03.2020	ÉFOÉSZ	5	11	Concept, spread, cancellation of olympics, medical care, ventilators, prevention	https://tinyurl.hu/Qbva
25.03.2020	FGR	12	6	Healthy lifestyle advisor	https://tinyurl.hu/gFrz
26.03.2020	ÉFOÉSZ	9	18	Hungarian translation of Inclusion Europe's information	https://tinyurl.hu/GyCH
26.03.2020	ÉFOÉSZ	2	5	Official coronavirus website, intensive care units, disinfectant production at MOL, new patient beds, use of face masks	https://tinyurl.hu/DmN2
27.03.2020	ÉFOÉSZ	4	36	Online advocacy group	https://tinyurl.hu/u3dn
27.03.2020	ÉFOÉSZ	24	18	Regulation, curfew, maintaining distance	https://tinyurl.hu/kg5S
27.03.2020	FGR	48	6	Curfew and shopping restrictions, information links so far	https://tinyurl.hu/lqf6
27.03.2020	ÉTA	2	1	Website collection portal	https://tinyurl.hu/NJEh
30.03.2020	ÉFOÉSZ	14	15	Contact details, symptoms, number of infected patients and deaths, curfew, maintaining distance, research results	https://tinyurl.hu/DL33
30.03.2020	FGR	7	2	Sharing of the AOSZ information collection page	https://tinyurl.hu/67fD
31.03.2020	ÉFOÉSZ	11	15	Concept, symptoms, number of infected patients and dead, legislation, shopping, staying at home, maintaining distance	https://tinyurl.hu/iY9e

Table 1 shows that *professionals and organisations actively involved in easy-to-understand communication produced content immediately. Professionals and organisations less active in the field of easy-to-access communication, recognising the importance of the situation, shared the sources of the content already developed.*

In reviewing the social content that appeared during the first phase of the health emergency, the number of shares increased when new content related to the state of emergency appeared alongside the original content:

- services available online (e.g. ÉFOÉSZ psychological counselling on 24.03.2020, ÉFOÉSZ distribution of 100 free masks on 06.05.2020),
- translations of information from abroad (e.g. translation of Inclusion Europe's material 26.03.2020),
- online advocacy activities (e.g. ÉFOÉSZ advocacy meeting 27.03.2020),
- films about activities you can do at home (e.g. ÉFOÉSZ advocacy home exercise – 09.04.2020, sharing of handwashing video by Farkasné dr. Rita Gönczi – 22.03.2020)
- guides for professionals working with people with intellectual disabilities (e.g. ÉFOÉSZ-01.04.2020, AOSZ-21.03.2020)
- descriptions of events and national holidays that fall during the period (e.g. description of the Easter holiday and related restrictions by Farkasné dr. Rita Gönczi – 10.04.2020, ham recipe – 11.04.2020)

LESSONS LEARNED FROM USING EASY-TO-UNDERSTAND COMMUNICATION IN A STATE OF EMERGENCY

In 2020, several practices were developed in the civil and institutional sector which still have an impact today. In addition to easy-to-understand content translations and stand-alone information materials, communication-friendly content for health professionals was developed.

As a professional, I was able to react the fastest to the imminent state of emergency based on the suggestion of Zsuzsanna Kovács, a special needs teacher, because I could directly publish the easy-to-understand information content I had developed without going through the organisational route. Individuals, organisations and institutions interested in easy-to-understand communication read it, so that they could immediately disseminate the initial information with a 'virus-like' speed. Individual speed also implied individual responsibility for the clarity and credibility of the information content. Single-person delivery also implies a strain on human resources, which in the long run allows for less frequent communication. Its effectiveness in the short term is in responding quickly and producing content at the request of readers, such as informing people living in the institution about communication opportunities. The national organisation for people with intellectual disabilities was the second to produce a poster, followed by a regular summary. Going down the organisational route was also a way to harness collaboration within the organisation, enabling the development of a user-friendly and understandable information platform. The process is slow but ensures sustainable communication over the long term.

The first period was devoted to content production, which was later taken over by the translation of international sources and the sharing of existing content with other organisations. Organisations, institutions and individuals who could not produce easy-to-understand content quickly, soon realised the value of increasing their impact through sharing. After the initial content was published, content producers distributed their own collections, while those involved in sharing created link collections based on uniform criteria. The reader's access to information was made more difficult by the need to monitor different channels. A good example of the development of a concentrated information base was the unified creation of a professional community coordinated by AOSZ, and the development of a jointly defined publication interface.

Based on the lessons learned, the following aspects should be considered for the use of easy to understand communication in the event of a future state of emergency:

- *Providing information quickly, simultaneously with the publication of common-language information.*
- The development of content that answers the questions raised increases the flow of information.
- The flow of information should be on a *transparent schedule and communication channel*. It is advisable to publish it on the *central information platform known to the person with intellectual disability and their environment*, or to compile a *collection of links* there.

- By *bringing together* professionals, organisations and institutions working in the field of easy to understand communication, and by *sharing tasks, coherent content* can be created.
- The information content prepared with easy to understand communication should have a *uniform structure* and layout so that the reader can navigate the content with confidence.
- It is advisable to include general information at all times, thus reinforcing repetition and memory retention.
- The dissemination and sharing of information on social media has been enhanced by the inclusion, alongside written information, of films, volunteer activities, descriptions of events and celebrations, etc. It is worthwhile increasing reading and sharing activity by sharing *alternative information* related to current topics in the periods between briefings.
- A *less frequent news release* following an initial dense information flow, such as one briefing per week, increases willingness to share. The almost daily briefing did not increase content dissemination, but rather kept the number of shares low.

Based on the experience of providing information through easy to understand communication during the recent health emergency, this series of recommendations aims to help ensure rapid and consistent access to information in a uniform and equal way in the event of another health emergency.

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