Fundación ONCE

UNIVERSITAT POLITÈCNICA DE CATALUNYA
BARCELONATECH
Accessibility Chair

JACCES

JOURNAL OF ACCESSIBILITY AND DESIGN FOR ALL

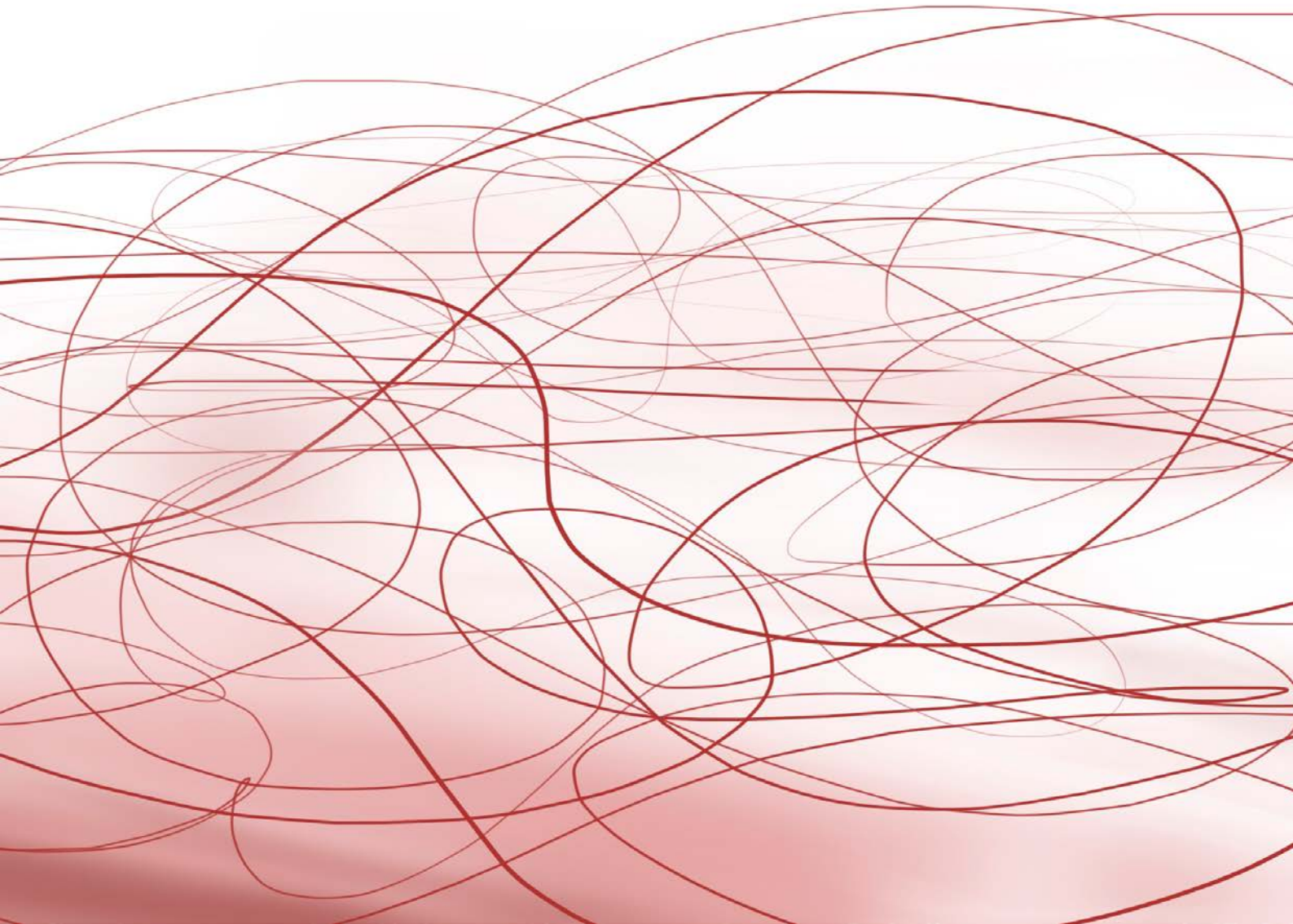
ISSN: 2013-7087

VOLUME 13 ISSUE 1

2023

DOI: 10.17411/jacces.v13i1

www.jacces.org



Journal of Accessibility and Design for All

Editorial Board

Office

Accessibility Chair

Universitat Politècnica de Catalunya · Barcelona Tech

Av. Víctor Balaguer, 1. 08800 Barcelona.

Telf. +34 93 896 78 31

jacces@catac.upc.edu

Twitter: @Journal_JACCES LinkedIn: JACCES page

www.jacces.org

(CC) JACCES, 2023. ISSN: 2013-7087

Table of contents

Journal of Accessibility and Design for All

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

THE INCLUSION OF SIGN LANGUAGE ON THE SWISS WEB ECO-SYSTEM

Bastien David[1]*, Lucía Morado Vázquez[2], and Elisa Casalegno[3]

[1,2,3] Department of Translation Technology (TIM), University of Geneva

[1]ORCID: 0000-0002-2105-7298, [2]ORCID: 0000-0002-0834-0734, [3]ORCID: 0000-0001-8797-2731

[1]bastien.david@unige.ch, [2]lucia.morado@unige.ch, [3]elisa.casalegno@unige.ch

*Corresponding author

Received: 2022-01-16 | Accepted: 2023-03-08 | Published: 2023-05-31

Abstract: Websites are a primary means of communication between public/private organisations and the general public. Therefore, websites must be accessible to all internet users to maximise their reach and efficacy, including those with hearing disabilities using sign language.

Around 10,000 deaf people and an equal number of non-deaf people – such as CODA, hard-of-hearing, interpreters, and relatives - communicate using sign language (SL) in Switzerland (SGB-FSS, 2016). SL is, in fact, the preferred means of communication among the deaf community for two primary reasons. SL provides greater detailed and accurate information than written communication for its deaf users, given its expressive nature and many deaf people consider it part of their identity. In modern society, the Web has revealed itself as a new medium to convey and receive information since its inception more than 30 years ago. However, little is known about the actual presence of SL in the Web, particularly in the Swiss web ecosystem.

This study showcases the preliminary results of our research into the presence of sign language in the Swiss web ecosystem. Looking at 97 websites of Swiss public institutions, universities, companies, news portals, and online shops, we investigated whether videos on their websites provided SL interpretation. We found that less than a third of the websites investigated had one or more videos. We then analysed the common characteristics of a subset of the videos (French-speaking Swiss SL videos) and checked whether they provided an equivalent of the websites' textual content. We found that those videos were mostly integrated on a web page dedicated to accessibility. They also had non-oral subtitles and were typically medical or legal-themed. Based on our results, we could

argue that the presence of SL in the Swiss web ecosystem is anecdotal, especially if compared with the amount of written information that is included on those websites.

Keywords: Web Accessibility, Switzerland, Sign Language, Multimedia

Introduction

Most deaf people use a national sign language (SL) as their first language. Up to 80% of them cannot successfully understand written content or have limited reading ability (World Federation of the Deaf, 2003; Debevc, Kožuh, Kosec, Rotovnik, & Holzinger, 2012, p. 213). Traditionally, hearing people without contact with the aforementioned minority probably suppose all deaf people read text easily. For example, they are convinced the Web is an accessible media by reading (Dotter, 2004, p. 206; Hilzensauer, 2006, pp. 184-5 and p. 199). Unfortunately, text on the Web can represent a significant barrier for people with reading difficulties such as the aforementioned deaf people, thus hindering their integration into hearing information's society (Debevc et. al., 2012, pp. 213-4; Yeratziotis & Zaphiris, 2018, p. 195).

In Switzerland, three sign languages are used by the deaf community: Swiss-German sign language (Deutschschweizerische Gebärdensprache, DSGS), French sign language of French-speaking Switzerland (Langue des signes française de Suisse Romande, LSF-SR) and Swiss-Italian sign language (Lingua dei Segni Italiana, LIS-SI). Although specific to Switzerland, these sign languages are similar to those of their neighbouring countries. In other words, DSGS is similar to the sign language used in southern Germany, LSF-SR is close to the sign language used in metropolitan France and similarly LIS to the sign language used in northern Italy (Braem & Rathmann, 2010, pp. 20-2).

Web Accessibility Standards and SL

Over the 30 years since its inception (CERN, 2019), the World Wide Web has proved to be a highly effective way of disseminating information. As such, many initiatives worldwide aim to make the Web a universally accessible tool. Arguably, the most important initiative has been the *Web Accessibility Initiative* (WAI) of the World Wide Web Consortium (W3C). The WAI has produced, among other resources, the *Web Content Accessi-*

bility Guidelines (WCAG). At the time of writing, the current version is 2.1, but an upcoming 2.2 version is soon to be announced, and a groundbreaking 3.0 version is also on the make. These continually updated guidelines have already been adopted by many countries, including Switzerland.

Together with national measures and international agreements, the WCAG aim to better integrate people with disabilities into society, including deaf people using SL.

Web Content Accessibility Guidelines (WCAG): International Standard

These guidelines provide a useful tool for developers and content creators to produce accessible websites. WCAG 2.1 includes 13 general guidelines organised around four principles, i.e., perceivable, operable, understandable and robust. Furthermore, these guidelines provide success criteria with three levels of compliance: A, AA, AAA (A being the lowest and AAA being the highest). Finally, the WCAG 2.1 also has a list of techniques that can be followed to meet the aforementioned success criteria (Kirkpatrick, O Connor, Campbell, & Cooper, 2018).

Only one of the WCAG 2.1 success criteria – 1.2.6 Sign Language (Prerecorded) – directly mentions sign language. This success criterion (SC) refers to the inclusion of sign language interpretation in prerecorded videos. It is classified as AAA and Kirkpatrick et al. (2018) acknowledge the benefits of including SL interpretation in prerecorded videos as they state that:

> *People whose human language is a sign language sometimes have limited reading ability. These individuals may not be able to read and comprehend the captions and thus require a sign language interpretation to gain access to the synchronised media content.*

No SC in WCAG 2.1 directly refers to the provision of SL videos signing the textual content of web pages. However, we could interpret that SC 3.1.5 *Reading Level* indirectly includes sign language in one of the five techniques that can be applied to meet it. SC 3.1.5 is also classified as AAA, and it specifically indicates that

> *When text requires reading ability more advanced than the lower secondary education level after removal of proper names and titles, supplemental content,*

> *or a version that does not require reading ability more advanced than the lower secondary education level, is available*. (Kirkpatrick et al., 2018)

One of the suggested techniques to meet this SC is G160, which suggests providing, '*sign language versions of information, ideas, and processes that must be understood in order to use the content'* (Cooper, Kirkpatrick, & O Connor, 2016).

As Dotter & Hilzensauer (2006, p. 46) had already stated "the needs of sing language users are not always sufficiently taken into consideration" in accessibility standards. We can also argue that the inclusion of SL is still not sufficiently covered under the WAI initiative/WCAG, and we can offer two reasons for this:

a) the inclusion of SL only features under the following two conditions: when there is a prerecorded video (SC 1.2.6) and when the textual content requires an advanced reading ability (SC 3.1.5).

b) the aforementioned success criteria (1.2.6 and 3.1.5) are classified as AAA, and national regulations that refer to the WCAG usually consider a web page to be 'accessible' if it complies with all the A and AA WCAG success criteria. This means that the inclusion of SL would not be obligatory under those national regulations. Additionally, the WAI mentions in another document that sign language *'is not required in most web accessibility policies'* (Henry, 2019).

Swiss Policy on Web Accessibility in SL

Web accessibility is central to current national and international policy discussions. In this section, we will examine the situation and legal framework in Switzerland concerning web accessibility in sign language.

International Agreements

Having ratified UN Convention on the Rights of Persons with Disabilities (CRPD) on the 15th of April 2014 (Swiss Confederation, 2014), Switzerland has accepted:

> [...] *to enable persons with disabilities to live independently and participate fully in all aspects of life, (…) shall take appropriate measures to ensure to persons with disabilities access (…) to information and communications, including*

> *information and communications technologies and systems (…) These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to (…) information, communications and other services, including electronic services and emergency services.* (CRPD 2006, Art. 9 §1)

National Measures

Before ratifying the UN Convention, the Swiss Confederation had already included in its constitution of 1999 that "The law shall provide for the elimination of inequalities that affect persons with disabilities" (Swiss Confederation 1999, Art. 8 §4). Furthermore, in 2002, the Federal Act for the *Elimination of Discrimination against People with Disabilities* (DDA) was approved. As its name suggests, this federal act had "[…] the purpose of preventing, reducing or eliminating discrimination against people with disabilities" (DDA 2002, Art. 1 §1). The Web is not explicitly discussed in this act, although there is a mention of online services in Article 14. This particular article describes the measures for people with speech, hearing or visual disabilities, and it begins by stating that:

> *In its dealings with the public, the authorities shall take account of the special concerns of persons with speech, hearing or visual disabilities.* (DDA 2002, Art. 14 §1)
>
> *Where they offer their services online, such services must be accessible to persons with visual disabilities without difficulty. The Federal Council shall issue the required technical regulations. It may declare technical standards to be binding for private organisations.* (DDA 2002, Art. 14 §2)

As it can be observed, although people with hearing disabilities are mentioned in the article, the reference to make online services accessible only refers to people with visual disabilities.

In 2005, the Federal IT Council acted the *Federal Guidelines for the Design of Accessible Websites* (P028) based on WCAG 1.0 (Lindenmeyer & Riesch, 2007, p. 7). The first version of the eCH-0059 accessibility standard was based on P028 (ibid, p. 1). This standard will be explained in the next section.

Other recent efforts to promote digital accessibility have been made by the Swiss administration. We can quote, among others, the *Digital Inclusion Summit* (DETEC, 2016), organised by the Federal Office for Equality for People with Disabilities and the Federal Office of Communications, which focused on improving website accessibility for people with disabilities. Furthermore, the Conference had sought the expertise of the Access for All Foundation. The publication of easy-to-read texts and the editing of videos in SL featured prominently among the measures presented, designed to improve internet access. Other recent conferences about digital accessibility include *For an Accessible Cyber-administration for All* (DFI, 2019) and *E-Accessibility* (DFI, 2020).

eCH-0059: Accessibility Swiss Standard

The Swiss eCH association, which includes representatives of the Swiss Confederation, all Swiss cantons, several universities, more than 120 businesses and public organisations (eCH, 2021), has developed a specific standard for digital accessibility, namely the eCH-0059 standard. This standard aims to make all public Internet services barrier-free for people with disabilities. The new version (3.0) has been recently approved (June 2020) and details the rules for creating and providing digital information and services in Switzerland (Lindenmeyer & Riesch, 2020, p. 6). It is tailored to organisations providing public services and applies to all their internet content and mobile applications (ibid. p. 5). The new version of the standard is based on the aforementioned WCAG 2.1, and it also draws on digital accessibility tools inspired by the Directive (EU) 2016/2102 (ibid. p. 2).

Section (2.4) of this standard focuses on alternative means of communication such as easy-to-read language and SL. The standard does not specify with which reading levels these alternative means could be used, but rather the type of content provided. It distinguishes between two types of content that should be provided in easy-to-read language and SL:

A) Information linked to the most important life areas. The standard stipulates that this content should be available in easy-to-read texts and SL videos. It could be information that has an impact on life and health, political and individual rights, preventing violence and ill-health, civil rights and duties, or directly addressed to people with disabilities.

B) Information related to other life areas. The standard indicates that this content should be available *proportionately* in easy-to-read texts and SL videos. It may be information

related to education, work, family, housing, leisure or public services (ibid, pp. 9-10). In this regard, we consider eCH-0059 to be one step ahead of WCAG 2.1 as it puts SL (and easy-to-read language) in a prominent position.

We can therefore conclude that, although eCH is based on WCAG 2.1, it gives more importance to the inclusion of SL on websites as it clearly describes the scenarios where it should be used and does not restrict its use to specific circumstances (prerecorded videos and text that require advanced reading abilities).

Research Objectives

As it can be deducted from the previous sections, we could state that there are several ongoing efforts being made on several fronts to attain a more accessible Web for SL users in Switzerland. Considering the aforementioned standard and the goal of the Swiss Research Centre for Barrier-Free Communication (Bouillon *et al.*, 2018) to foster SL inclusion, our objective is twofold. We would like to first determine the current situation of the SL in the Swiss web ecosystem and then explore, if present, some different techniques adopted for this inclusion. During our research, we organised our investigation around the following research questions:

Question 1 (Q1): Do the websites contain videos with SL?

Question 2 (Q2): How were the SL videos integrated on the web page and what are their main characteristics?

Question 3 (Q3): Do the SL videos provide an equivalent of the textual content of the web pages?

The paper is structured as follows: the *Methodology* section explains the methods applied during the Swiss websites' inspection to address our research questions, two subsections present the dataset, and the corpus examination method followed. The *Results* section presents and discusses the results obtained and answers the central questions, and the final section deals with conclusion and future work.

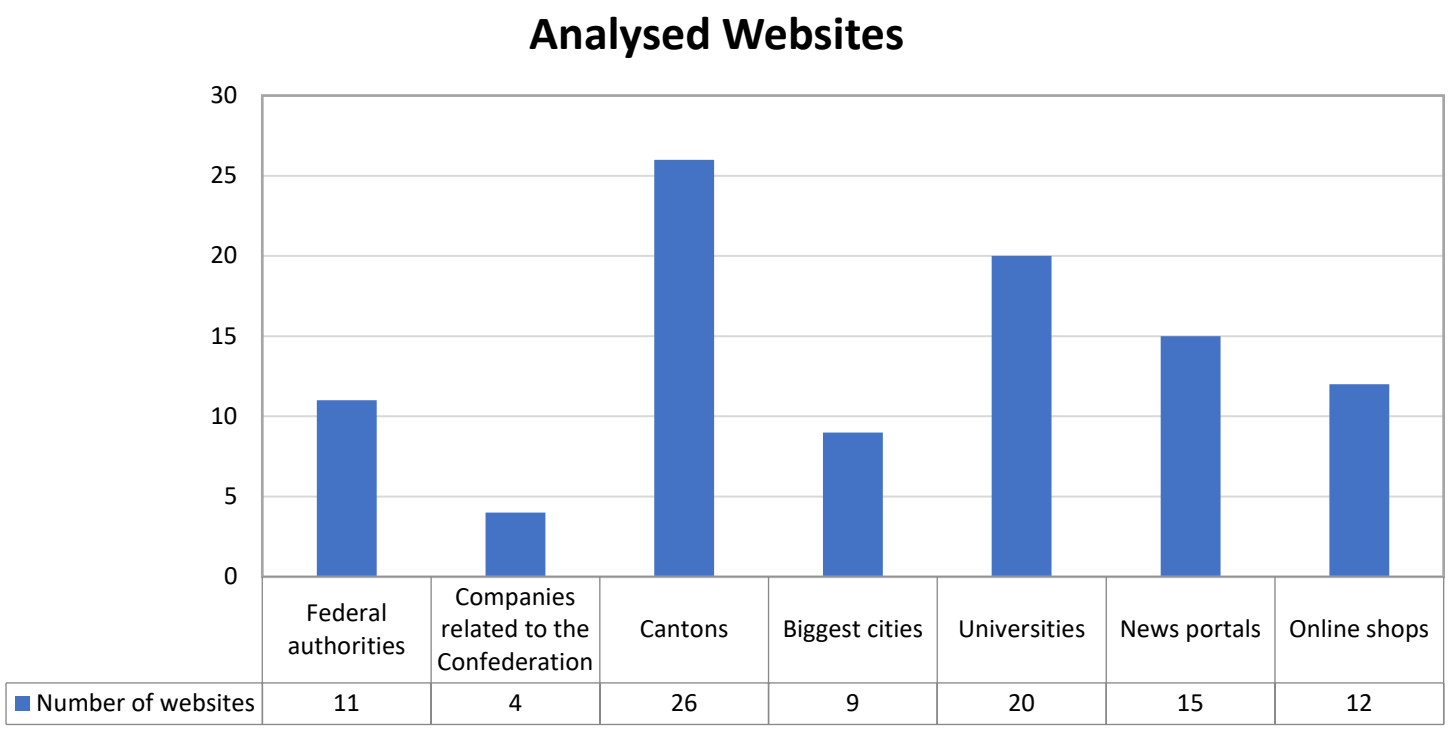
Methodology

In order to answer our research questions, the current study utilised a mixed methods approach. Firstly, we examined a corpus of 97 Swiss websites to check the presence of SL videos. Secondly, we conducted a qualitative analysis of a subset of the videos retrieved from the first phase. What follows is a description of the corpus and the data collection and analysis put in place.

Corpus

We analysed a corpus made of 97 multilingual and monolingual websites that were included in the *Swiss Accessibility Study 2016*, carried out by the Swiss organisation, Access for All (Bolfing et al., 2016). Although the original study claimed to include 100 websites (Bolfing et al., 2016, p. 21), we only found 99 in their public report. Furthermore, one of the websites featured in two different categories (we included Basel City and Canton's website in only the 'Cantons' category), and another website was no longer available when we conducted our study. Ultimately, our corpus comprised 97 unique websites. The complete list of analysed websites can be consulted in Appendix A. These 97 websites from the original study were divided into seven categories, i.e., Federal authorities, companies related to the Confederation, Swiss cantons, the nine biggest cities (Basel was not included as previously noted), universities, news portals, and online shops. The distribution of websites (Figure 1) is not equal between all these categories: there are 26 canton's websites (26.8%), 20 universities' (20.6%), 15 news portals' (15.2%), 12 online shops' (12.4%), 11 Federal authorities (11.3%), 9 biggest cities (9.3%), 4 companies related to the Confederation (4.1%).

Figure 1. Analysed Websites per Category.



The dataset reflected the multilingual nature of Switzerland. Our first inspection enabled us to identify 55 multilingual websites and 42 monolingual websites (29 in German, 9 in French and 4 in Italian). As we can see in Figure 2, four of the aforementioned categories (Federal authorities, companies related to the Confederation, universities and online shops) included the highest percentage of multilingual websites.

Figure 2. Monolingual and Multilingual Websites.

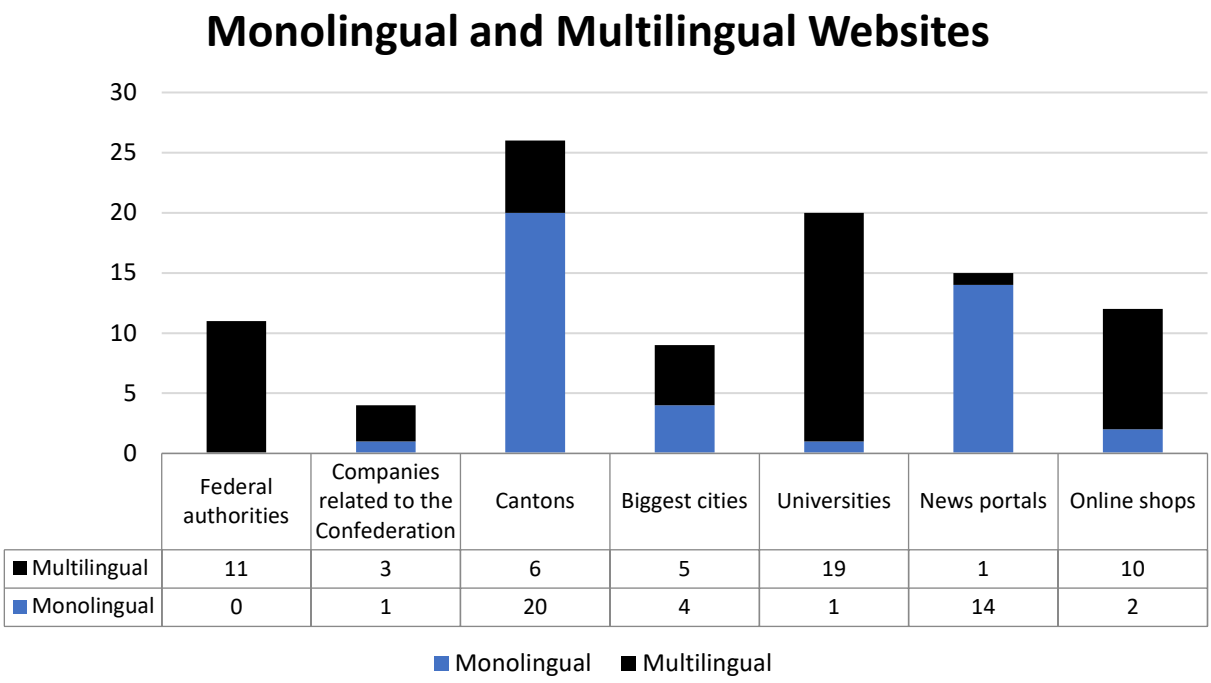
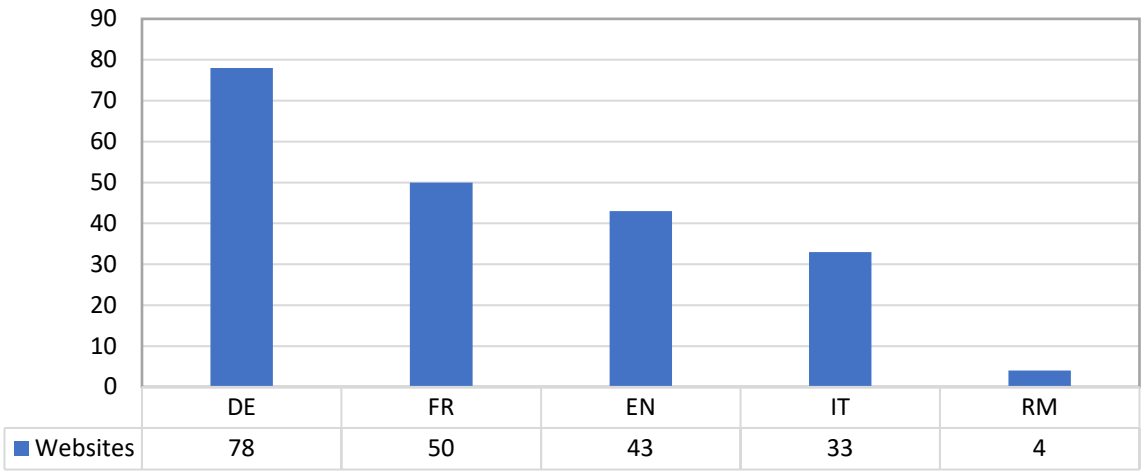


Figure 3 shows that, in our dataset, German was the most used language (78 of the 97 websites, 80.4%), followed by French (50 websites, 51.5%), English (43 websites, 44.3%), Italian (34 websites, 34 %), and Romansch (4 websites, 4.1%).

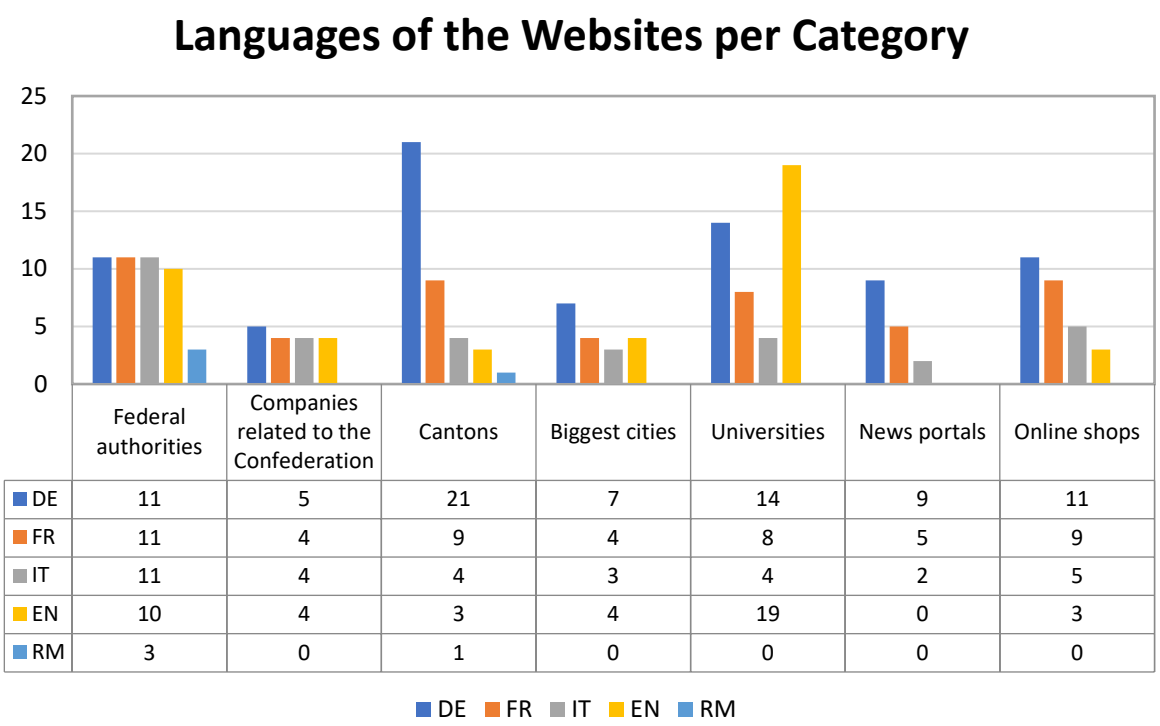
Figure 3. Language of the Websites.



The languages are also unevenly distributed within website categories, as shown in Figure 4. The four Swiss national languages (German, French, Italian and Romansch) are present on three of the Federal authorities' websites and in one of the cantons. English

is particularly present among universities' websites (19/20 websites) and the Federal authorities' websites.

Figure 4. Languages of the Website per Category.



	Federal authorities	Companies related to the Confederation	Cantons	Biggest cities	Universities	News portals	Online shops
DE	11	5	21	7	14	9	11
FR	11	4	9	4	8	5	9
IT	11	4	4	3	4	2	5
EN	10	4	3	4	19	0	3
RM	3	0	1	0	0	0	0

Corpus examination

We manually viewed and searched for keywords in the four language versions of the websites. Each language variant of the website was studied independently, i.e., if a website was available in French and English, we conducted two separate visual and keyword inspections in each language. Overall, we conducted 204 individual inspections in our corpus: 78 in German (DE), 50 in French (FR), 43 in English (EN), and 33 in Italian (IT). Websites were studied by three researchers according to their language combinations, ranging from October 2020 to March 2021 for French and English versions and February to March 2021 for German and Italian versions. SL videos from the French dataset were analysed between mid-February and mid-March 2021 and consolidated in August 2021. Researchers conducted the inspections independently and met regularly to compare outcomes, share uncertainties and agree on results.

We used two main search methods to examine each site: a) an internal search option of each website (whenever available), b) the Google Search engine and "site" function to

restrict our search. As shown in Table 1, we used two/three keywords per language. Firstly, we searched for the general term 'accessibility' in each corresponding language version to see if we could find an 'accessibility statement' (Abou-Zahra, Velleman, Antonisse & de Bruin, 2021) that would include information about the website's accessibility and the potential presence of SL. Secondly, we used the keywords 'sign language' in each language. We examined the first 30 results of each individual query and included our findings using a predefined and shared template.

Table 1. Multilingual Keywords Used for this Study

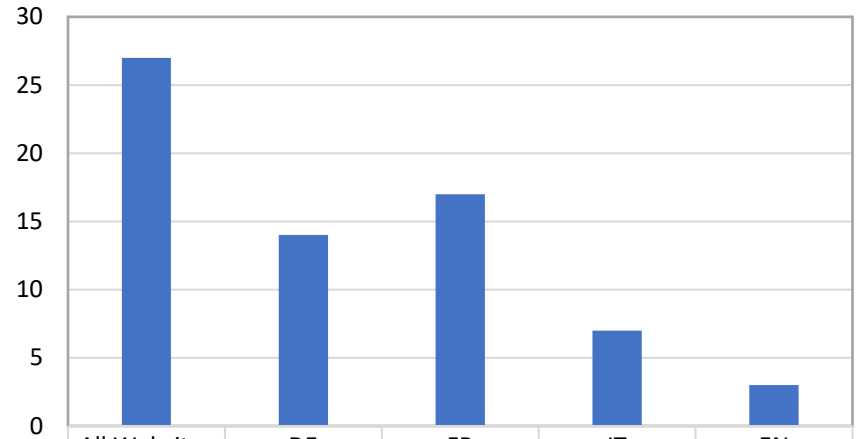
English	French	German	Italian
"accessibility"	"accessibilité"	"Zugänglichkeit" "Barrierefreiheit"	"accessibilità"
"sign language"	"langue des signes"	"Gebärdensprache"	"lingua dei segni"

Results

Presence of SL on specific websites

Overall, we found the presence of one or more SL videos in 27/97 websites (27.8%). In terms of individual languages, Figure 5 shows how we found one or more videos containing SL in 14/78 websites (17.9%) in German. In the French corpus, 17/50 websites (34%) contained videos in SL. In the Italian corpus, we found SL videos on 7/33 websites (21.2%). Lastly, in the English corpus, only 3/43 websites (7%) contained at least one video in SL.

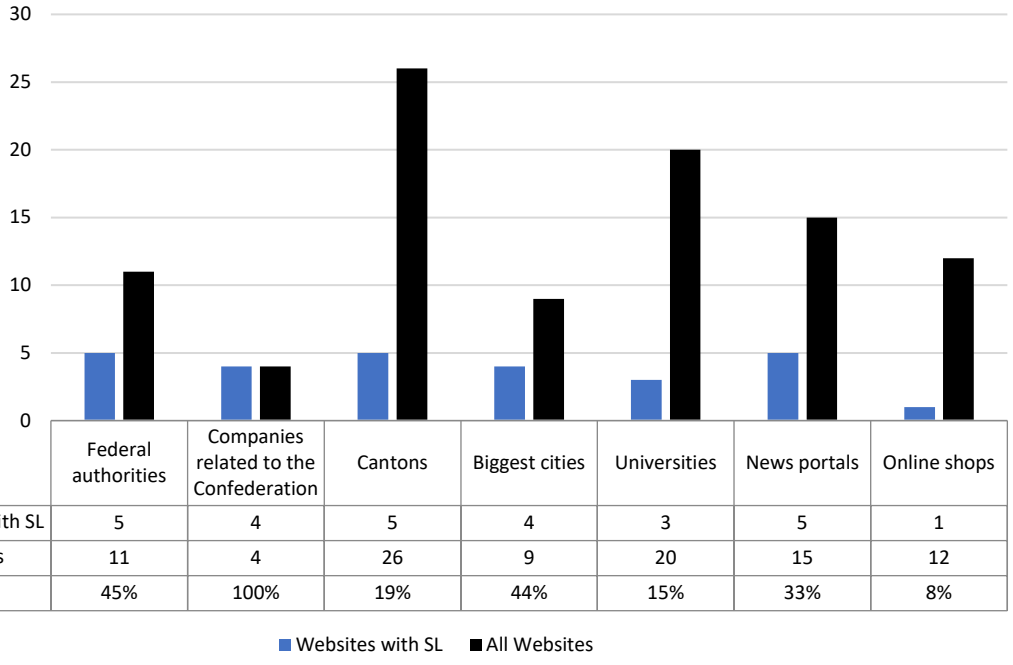
Figure 5. Presence of SL Videos in our Corpus.



	All Websites	DE	FR	IT	EN
Websites with SL videos	27	14	17	7	3
% of Websites with SL videos	27,8%	17,9%	34,0%	21,2%	7,0%

In terms of website category, as shown in Figure 6, those 27 websites containing SL videos belong to all the studied categories: Federal authorities (5), companies related to the Confederation (4), cantons (5), biggest cities (4), universities (3), news portals (5) and online shops (1).

Figure 6. Presence of SL per Website Category.



	Federal authorities	Companies related to the Confederation	Cantons	Biggest cities	Universities	News portals	Online shops
Websites with SL	5	4	5	4	3	5	1
All Websites	11	4	26	9	20	15	12
%	45%	100%	19%	44%	15%	33%	8%

These initial raw results provide a partial response to our question about the presence of SL in the Swiss web ecosystem, which we can consider scarce as we did not find any

video in SL in 70 of the 97 analysed websites in any of their language versions. Moreover, we observed that they are very different in terms of topic, integration, or SL used, and not all of them represented an alternative means of communication. For example, SL might have only been featured in a news report specifically about SL, but not all the information present in the video was SL interpreted. Further exploring the initial results, we looked at how the websites incorporated a subset of those videos, their primary characteristics such as the SL used, the signer's position and the video's topic (Q2), and whether they provided an equivalent of the web page's textual content (Q3). The results from that second analysis are presented in the next section.

Description and Integration of Videos

In the second part of our study, we present the results of the qualitative analysis of SL videos in only the French websites. We composed a second corpus comprising the 43 SL videos that were found on 17 French websites. Appendix B provides a list of the videos analysed and the results.

As previously mentioned, these videos were analysed in mid-March 2021 and consolidated in August 2021. The period between our first data inspection and the qualitative analyses led to some changes in our dataset. For example, SBB/CFF/FFS, the Swiss railways company, integrated a new article (30.11.2020) about its accessible movie projects, including five GIFS videos in Swiss French SL.

More than half of the videos (n=24, 55.8%) were found on Federal authorities' websites, almost a quarter (n=9, 20.9%) on Swiss cantons' websites, six videos (13.9%) on the websites of companies related to the Confederation and four videos (9.3%) in universities' websites. We did not find any SL video on the biggest cities' websites. This analysis did not include results from news portals and e-shops that were not publicly available as a subscription was required to consult them. Results from this sub-dataset analysis helped us answer our second and third research questions, i.e., *how were SL videos integrated on the web page*? And *Do the SL videos provide an equivalent of the textual content of the web pages?*

Video integration

The majority of the videos (37/43, 86%) were hosted on online video platforms: YouTube (28/37, 75.7%), Vimeo (5/37, 13.5%) and SWITCHtube (4/37, 10.8%) for higher education videos in Switzerland. More than half of the videos found were integrated into the web page (28/43, 65.1%) and could be watched directly by the user, and almost half of them were available in both (22/43, 51.1%). Concerning the 15 videos that were not included on their web page, hypertext links were used to redirect users to video platforms or external web pages. However, this might not be the best technique to integrate SL videos as Debevc, Kosec and Holzinger (2011) pointed out that "[they] may interrupt user's visual contact/focus with the content beneath." (p. 187).

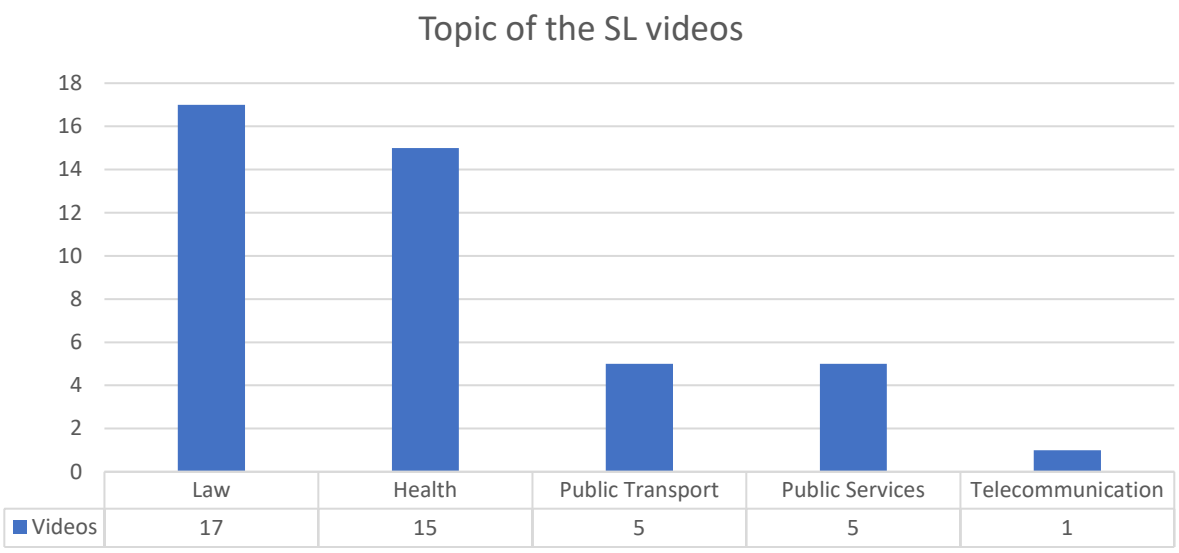
Sign Language variant and multimodal data

As expected, most of the videos found were interpreted into Swiss-French Sign Language (42/43, 97.6%). However, Swisscom, a Swiss telecommunication company, mixed German speech with French subtitles and Swiss-German Sign Language in a video advertisement (Appendix B, swi01). Concerning multimodal data, 28 videos (65.1%) included French captions. More than half of the videos (n=27, 62.8%) did not include verbal language. While 17 of those 27 provided captions, the remaining 10 did not include any captions and therefore were only accessible to SL users.

Topics covered

Five main topics were identified in the analysis of the videos: Health, Law, Public Transport, Public Services and Telecommunication. As can be observed in Figure 7, Law (39.5%, 17 videos) and Health (34.8%, 15 videos) were the most represented topics in our dataset. The higher representation of health-related videos is undoubtedly directly associated with the COVID-19 pandemic (13 videos). These results are in line with the topics mentioned in section 2.4 of the Swiss eCH-0059 standard in terms of providing alternative communication as easy-to-read texts and SL videos in the most important life areas, i.e., "life and health, politics and individual rights, (…) and health prevention, civil rights and obligations" (Lindenmeyer & Riesch, 2020, pp. 9-10).

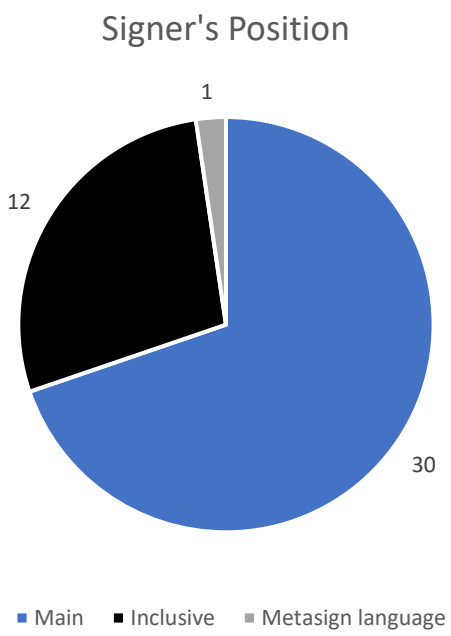
Figure 7. Topic of the LS Videos in the French Websites.



Signer position

The signer position (SL users or interpreter) is a crucial aspect that should be taken into account when recording a video. This position depends on the video context and the place of his/her intervention. We identified three different position categories in our dataset, namely Main, Inclusive and Metasign language. As we can see in Figure 8, in most cases (69.7%, 30 videos) the position was identified as 'Main', which means that the signer was on either the side of the screen or centred. He/she could be considered as the primary speaker of the video. In the case of the 'Inclusive' position (27.9%, n=12), the signers appeared to complete animation videos or other short videos. In those cases, the signer's position was included after the short video or on a specific window and placed on the side of the screen. In the Metasign category we found one video (2.3%). The video shows a signer being interviewed and signing, but the content of that video as a whole was not interpreted on SL. This type of video was not directly targeting SL users, as the signer was not really conveying the main information of the video.

Figure 8. Signer's Position of the SL Videos in the French Websites.



Discussion and Conclusion

This research deepens our knowledge of the presence of SL on the Web and sheds new light on the presence of SL in the Swiss website ecosystem. As far as we know, there was no information available regarding the presence of SL in the Swiss web ecosystem prior to this study.

We conducted a multilingual inspection in a corpus of 97 Swiss websites and found the presence of one or more SL videos in less than a third of them. Our first research question concerned the presence of videos with SL in the Swiss ecosystem. Our initial results confirmed it, but we must clarify that this is still a scarce presence.

A first look at the initial results showed us that not all sign language videos on the Swiss web ecosystem share the same characteristics. Therefore, to answer our second research question, we set up a descriptive *strategy vis-à-vis* the sign language videos on the French-speaking Swiss web. We found out that website managers use direct video integration on their website (28/43, 65.1%), hyperlinks to external resources (37/43, 86%) with links to other pages including videos or video platforms (such as Vimeo or YouTube), or both solutions (22/43, 51.1%).

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

Swiss-French websites predominantly integrate SL videos in Swiss-French sign language (42/43, 97.6%). One of the most represented topics is health, specifically the COVID-19 health crisis (15/43, 34.8%). The signer's physical position in the video is also important as it helps determine whether the media was designed for the deaf or whether it was adapted while being recorded or later. Most videos provide a signer with a main role (30 videos, 69.7%). Centred or on the side of the screen, we consider him/her as the main speaker. 12 videos (27.9%) included the interpreter after the main video clip, and one video (2.3%) provided a short sign language intervention but the content of the video as a whole was not available in SL.

Checking if the textual content on all the websites was equally represented by SL videos, as per the new version of eCH-0059 for some types of content, would have exceeded the scope of this preliminary study. However, our inspection of the websites and their SL videos has provided a partial response to our third research question and suggests that the amount of information in SL videos is merely anecdotal, especially if we compare it with the amount of content that was included in textual form on those websites.

Considering all our results, we have seen that despite the fact that the current Swiss legal framework and the new version of the eCH-0059 standard aim to promote the accessibility of the Web content in the Swiss context, the presence of SL content in this medium is still anecdotal. Having said that, we salute the effort that all these institutions have made to include SL videos on their websites, and we consider it the first step towards a more inclusive society. We would also like to commend the Swiss Federal Office of Public Health's (FOPH) efforts during the Covid-19 health crisis to make the information accessible to different sign languages and easy-to-read languages (DE, FR, IT, EN). The FOPH demonstrated how to develop and provide accessible alternative information for signing deaf people, such as summarising text to sign language or simplifying it to easy-to-read language.

The present research has only considered the Swiss web context and its second step only covered the videos found in the French queries. Therefore, a natural progression of this work would be to extend the corpus of websites and to study the SL videos found in the other language queries. Our corpus could be extended to include the most visited websites in Switzerland and/or other countries, following some well-known rankings like the Alexa top 500 sites on the Web (Alexa Internet, Inc., 2021) or websites that belong to certain categories (e.g. universities' websites). Furthermore, it would be interesting to

repeat the study in 2022 to observe if the application of the new eCH-0059 standard has served as a catalyst for the production and inclusion of SL videos on the Swiss web ecosystem.

Our study methodology relied on an initial keyword search, which we hypothesised a user searching for SL videos might use. This method might not always be reliable if those keywords do not appear close to the sign language videos, but regular users applying the same search method would encounter the same barrier. Moreover, when our query offered multiple results, we only analysed the initial 30 results, again hypothesising that a regular user might not go over that limitation. To overcome these flaws, in future iterations of this study, we could implement two different additional methodological approaches. The first approach would involve studying the current navigation and search practices of SL signers on the Web. This user-based study would help us better understand how they make use of the Web in general and how they specifically access SL video content. The second approach could entail a survey among the web and communication managers of the studied websites. This second study would enable us to obtain first-hand data from the videos included on their websites and gather more information about their implementation strategies and general policies on this topic.

The multilingual nature of Switzerland and our datasets has created new research questions that cover this multilingual aspect and which would be worth exploring further: 1) Is SL more present in one particular language version? 2) Is the SL used or its dialectal variant specified and coherent with the text around it?

Finally, future research should undoubtedly include members of the Swiss deaf community to investigate their real needs and experience with the usage of Swiss websites. To conclude, this initial study can serve as a base for future studies that investigate the presence of SL videos in the web.

Acknowledgements

This research study was conducted as part of the research project UNI-ACCESS, in the framework of the “P-7 Diversity, inclusion and equal opportunities in university development (2021-2024)” funded by Swissuniversities. We would like to express our gratitude to the other members of the project for their valuable feedback.

References

[1] Abou-Zahra, S., Velleman, E., Antonisse, R., & de Bruin, B. (2021). Developing an Accessibility Statement. *Web Accessibility Initiative WAI. Strategies, Standards, Resources to Make the Web Accessible to People with Disabilities*. Retrieved May 19, 2021, from https://www.w3.org/WAI/planning/statements/

[2] Alexa Internet, Inc. (2021). Top Sites for Countries. *Alexa: The Top 500 Sites on the Web*. Retrieved May 31, 2021, from https://www.alexa.com/topsites/countries

[3] Bouillon, P., Rodriguez Vazquez, S., & Strasly, I. (2018). Developing a New Swiss Research Centre for Barrier-Free Communication. In Pérez-Ortiz, Sánchez-Martínez, Esplà-Gomis, Popovic, Rico, Martins, Van den Bogaert, et al. (Eds.), Proceedings of the 21st Annual Conference of the European Association for Machine Translation. Alacant (Spain)—28-30 May 2018 (p. 347). Presented at the Proceedings of the 21st Annual Conference of the European Association for Machine Translation. Alacant (Spain) - 28-30 May 2018, Alacant (Spain).

[4] Braem, P. B., & Rathmann, C. (2010). Transmission of Sign Languages in Northern Europe. In D. Brentari (Ed.), *Cambridge Language Surveys: Sign Languages* (1st ed., pp. 19–45). Cambridge University Press. Retrieved March 17, 2021, from https://www.cambridge.org/core/product/identifier/CBO9780511712203A012/type/book_part

[5] CERN. (2019). 30th Anniversary of the World Wide Web. *CERN Accelerating science*. Retrieved March 29, 2021, from https://home.cern/events/web30

[6] Cooper, M., Kirkpatrick, A., & O Connor, J. O. (2016). G160: Providing Sign Language Versions of Information, Ideas, and Processes that Must Be Understood in order to Use the Content | Techniques for WCAG 2.0. *W3C Recommendation*. Retrieved June 1, 2021, from https://www.w3.org/TR/2016/NOTE-WCAG20-TECHS-20160317/G160.html

[7] Debevc, M., Kosec, P., & Holzinger, A. (2011). Improving Multimodal Web Accessibility for Deaf People: Sign Language Interpreter Module. *Multimedia Tools and Applications*, *54*(1), 181–199.

[8] Debevc, M., Kožuh, I., Kosec, P., Rotovnik, M., & Holzinger, A. (2012). Sign Language Multimedia Based Interaction for Aurally Handicapped People. In K. Miesenberger, A. Karshmer, P. Penaz, & W. Zagler (Eds.), *Computers Helping People with Special Needs*, Lecture Notes in Computer Science (Vol. 7383, pp. 213–220). Berlin, Heidelberg: Springer Berlin Heidelberg. Retrieved December 7, 2020, from http://link.springer.com/10.1007/978-3-642-31534-3_33

[9] DETEC. (2016). The Federal Government is committed to a digital Switzerland of equal opportunities. *Federal Department of the Environment, Transport, Energy and Communications DETEC*. Retrieved October 4, 2021, from https://www.uvek.admin.ch/uvek/en/home/detec/media/press-releases.msg-id-63805.html

[10] DFI. (2019). Cyberadministration accessible. *Département fédéral de l'intérieur DFI*. Retrieved October 4, 2021, from https://www.edi.admin.ch/edi/fr/home/fachstellen/aktuell/themen-der-gleichstellung1/e-accessibility-/fachttagungendesebgb/barrierefreies-e-government-.html

[11] DFI. (2020). Colloque du 5 novembre 2020: « E-accessibilité ». *Département fédéral de l'intérieur DFI*. Retrieved October 4, 2021, from https://www.edi.admin.ch/edi/fr/home/fachstellen/aktuell/themen-der-gleichstellung1/e-accessibility-/fachttagungendesebgb/fachtagung_5_11_2020.html

[12] eCH. (2021). L'association. *E-Government Standards eCH*. Retrieved May 19, 2021, from https://www.ech.ch/index.php/fr/lassociation

[13] Henry, S. L. (2019). Sign Languages. *Web Accessibility Initiative WAI. Strategies, Standards, Resources to Make the Web Accessible to People with Disabilities*. Retrieved August 3, 2021, from https://www.w3.org/WAI/media/av/sign-languages/

[14] Kirkpatrick, A., O Connor, J. O., Campbell, A., & Cooper, M. (2018). Web Content Accessibility Guidelines WCAG 2.1. *W3C Recommendation*. Retrieved June 1, 2021, from https://www.w3.org/TR/WCAG21/

[15] Lindenmeyer, J., & Riesch, M. (2007). ECH-0059 Accessibility Standard 1.0. *E-Government Standards eCH*. Retrieved from https://ech.ch/fr/dokument/a2d5fdc1-31a2-4ba1-9b7e-290f6216c2d1

[16] Lindenmeyer, J., & Riesch, M. (2020). ECH-0059 Accessibility Standard 3.0. *E-Government Standards eCH*. Retrieved from https://ech.ch/fr/dokument/e2896a60-9489-4662-9ba9-be5ddb430f31

[17] Swiss Confederation. (2014). RS 0.109—Convention du 13 décembre 2006 relative aux droits des personnes handicapées. *La plateforme de publication du droit fédéral Fedlex*. Retrieved September 14, 2021, from https://www.fedlex.admin.ch/eli/cc/2014/245/fr

[18] World Federation of the Deaf. (2003). Position Paper regarding the United Nations Convention on the Rights of People with Disabilities. *Enable United Nations*. Retrieved April 12, 2021, from https://www.un.org/esa/socdev/enable/rights/contrib-wfd.htm

[19] Yeratziotis, A., & Zaphiris, P. (2018). A Heuristic Evaluation for Deaf Web User Experience HE4DWUX. *International Journal of Human-Computer Interaction*, *34*(3), 195–217.

Appendices

Appendix A. All Data Collect

Website	Institution/Company	Category	FR-LS	IT-LS	EN-LS	DE-LS	LS Total*
www.meteoschweiz.admin.ch	Bundesamt für Meteorologie und Klimatologie MeteoSchweiz	Fed. Aut.	N	N	N	N	N
www.bsv.admin.ch	Bundesamt für Sozialversicherungen	Fed. Aut.	N	N	N	N	N
www.bger.ch	Bundesgericht	Fed. Aut.	N	N	N/A	N	N
www.ch.ch	ch.ch	Fed. Aut.	Y	Y	N	Y	Y
www.edi.admin.ch	Eidgenössisches Departement des Innern	Fed. Aut.	Y	Y	N	Y	Y
www.eda.admin.ch	Eidgenössisches Departement für auswärtige Angelegenheiten	Fed. Aut.	N	N	N	N	N
www.uvek.admin.ch	Eidgenössisches Departement für Umwelt, Verkehr, Energie und Kommunikation	Fed. Aut.	Y	Y	N	Y	Y
www.vbs.admin.ch	Eidgenössisches Departement für Verteidigung, Bevölkerungsschutz und Sport	Fed. Aut.	N	N	N	N	N
www.wbf.admin.ch	Eidgenössisches Departement für Wirtschaft, Bildung und Forschung	Fed. Aut.	Y	N	N	N	Y
www.efd.admin.ch/	Eidgenössisches Finanzdepartement	Fed. Aut.	N	N	N	N	N

Website	Institution/Company	Category	FR-LS	IT-LS	EN-LS	DE-LS	LS Total*
www.ejpd.admin.ch	Eidgenössisches Justiz- und Polizeidepartement	Fed. Aut.	Y	**Y**	N	Y	Y
www.postfinance.ch	PostFinance	Companies	N	N	N	N	N
www.srf.ch	Schweizer Radio und Fernsehen	Companies	N/A	N/A	N/A	Y	Y
www.sbb.ch	Schweizerische Bundesbahnen SBB	Companies	Y	N	N	N	Y
www.post.ch	La Poste	Companies	Y	N	N	Y	Y
www.swisscom.ch	Swisscom	Companies	Y	N	N	Y	Y
www.ag.ch	Aargau	Cantons	N/A	N/A	N/A	N	N
www.ar.ch	Appenzell Ausserrhoden	Cantons	N/A	N/A	N/A	N	N
www.ai.ch	Appenzell Innerrhoden	Cantons	N/A	N/A	N/A	N	N
www.bl.ch	Basel	Cantons	N/A	N/A	N/A	N	N
www.bs.ch	Basel-stadt	Cantons	N	N	N	N	N
www.be.ch	Bern	Cantons	N	N/A	N/A	N	N
www.fr.ch	Fribourg	Cantons	N	N/A	N/A	N	N
www.ge.ch	Genève	Cantons	N	N/A	N/A	N/A	N
www.gl.ch	Glarus	Cantons	N/A	N/A	N/A	N	N
www.gr.ch	Grisons	Cantons	N/A	N	N	N	N
www.ju.ch	Jura	Cantons	N	N/A	N/A	N/A	N

Website	Institution/Company	Category	FR-LS	IT-LS	EN-LS	DE-LS	LS Total*
www.lu.ch	Luzern	Cantons	N/A	N/A	N/A	Y	Y
www.ne.ch	Neuchâtel	Cantons	Y	N/A	N/A	N/A	Y
www.nw.ch	Nidwalden	Cantons	N/A	N/A	N/A	N	N
www.ow.ch	Obwalden	Cantons	N/A	N/A	N/A	N	N
www.sh.ch	Schaffhausen	Cantons	N/A	N/A	N/A	N	N
www.sz.ch	Schwyz	Cantons	N/A	N/A	N/A	N	N
www.so.ch	Solothurn	Cantons	N/A	N/A	N/A	N	N
www.sg.ch	St. Gallen	Cantons	N/A	N/A	N/A	N	N
www.tg.ch	Thurgau	Cantons	N/A	N/A	N/A	N	N
www.ti.ch	Ticino	Cantons	N/A	N	N/A	N/A	N
www.ur.ch	Uri	Cantons	N/A	N/A	N/A	N	N
www.vs.ch	Valais	Cantons	Y	N/A	N/A	N	Y
www.vd.ch	Vaud	Cantons	Y	N/A	N/A	N/A	Y
www.zg.ch	Zug	Cantons	N	N	N	N	N
www.zh.ch	Zürich	Cantons	N/A	N/A	N/A	Y	Y
www.bern.ch	Bern (stadt)	Biggest cities	N	N	N	Y	Y
www.biel-bienne.ch	Bienne	Biggest cities	Y	N/A	N	N	Y

Website	Institution/Company	Category	FR-LS	IT-LS	EN-LS	DE-LS	LS Total*
www.bs.ch	Basel-stadt	Biggest cities	N/A	N/A	N/A	N/A	N/A
www.ville-geneve.ch	Genève (ville)	Biggest cities	Y	N	N/A	N	Y
www.lausanne.ch	Lausanne	Biggest cities	N	N/A	N/A	N/A	N
www.lugano.ch	Lugano	Biggest cities	N/A	N	N/A	N/A	N
www.stadtluzern.ch	Luzern (stadt)	Biggest cities	N/A	N/A	N/A	N	N
www.stadt.sg.ch	St. Gallen (stadt)	Biggest cities	N/A	N/A	N	N	N
stadt.winterthur.ch	Winterthur	Biggest cities	N/A	N/A	N/A	N	N
stadt-zuerich.ch	Zürich (stadt)	Biggest cities	N/A	N/A	Y	Y	Y
www.epfl.ch	École Polytechnique Fédérale de Lausanne	Universities	N	N/A	N	N/A	N
www.ethz.ch	Eidgenössische Technische Hochschule Zürich	Universities	N/A	N/A	N	N	N
www.usi.ch	Università della Svizzera italiana	Universities	N/A	N	N	N/A	N
www.unibas.ch	Universität Basel	Universities	Y	N/A	N	Y	Y
www.unibe.ch	Universität Bern	Universities	N	N/A	N	N	N
www.unilu.ch	Universität Luzern	Universities	N/A	N	N	N	N
www.unisg.ch	Universität St. Gallen	Universities	N/A	N/A	Y	Y	Y
www.uzh.ch	Universität Zürich	Universities	N/A	N/A	Y	Y	Y
www.unifr.ch	Université de Fribourg	Universities	N	N/A	N	N	N

Website	Institution/Company	Category	FR-LS	IT-LS	EN-LS	DE-LS	LS Total*
www.unige.ch	Université de Genève	Universities	N	N/A	N	N/A	N
www.unil.ch	Université de Lausanne	Universities	N	N/A	N	N/A	N
www2.unine.ch	Université de Neuchâtel	Universities	N	N/A	N	N/A	N
www.bfh.ch	Berner Fachhochschule / Haute école spécialisée bernoise	Universities	N	N/A	N	N	N
www.fhnw.ch	Fachhochschule Norwestschweiz	Universities	N/A	N/A	N	N	N
www.ffhs.ch	Fernfachhochschule Schweiz	Universities	N/A	N/A	N	N	N
www.htwchur.ch	Hochschule für Technik und Wirtschaft Chur	Universities	N/A	N/A	N	N	N
www.hslu.ch	Hochschule Luzern	Universities	N/A	N/A	N	N	N
www.kalaidos-fh.ch	Kalaidos Fachhochschule Schweiz	Universities	N/A	N/A	N/A	N	N
www.supsi.ch	Scuola universitaria professionale della Svizzera italiana	Universities	N/A	N	N	N/A	N
www.zhaw.ch	Zürcher Hochschule für Angewandte Wissenschaften	Universities	N	N	N	N	N
www.20min.ch	20 Minutes/ Minuten	News portals	Y	N/A	N/A	N	Y
www.24heures.ch	24 heures	News portals	Y	N/A	N/A	N/A	Y
bazonline.ch	Basler Zeitung	News portals	N/A	N/A	N/A	N	N
www.blick.ch	Blick	News portals	N/A	N/A	N/A	N	N
www.bernerzeitung.ch	Berner Zeitung	News portals	N/A	N/A	N/A	N	N

Website	Institution/Company	Category	FR-LS	IT-LS	EN-LS	DE-LS	LS Total*
www.cdt.ch	Corriere del Ticino	News portals	N/A	Y	N/A	N/A	Y
www.derbund.ch	Der Bund	News portals	N/A	N/A	N/A	N	N
www.laregione.ch	La regione	News portals	N/A	Y	N/A	N/A	Y
www.lematin.ch	Le matin	News portals	N	N/A	N/A	N/A	N
www.letemps.ch	Le temps	News portals	Y	N/A	N/A	N/A	Y
www.luzernerzeitung.ch	Neue Luzerner Zeitung	News portals	N/A	N/A	N/A	N	N
www.nzz.ch	Neue Zürcher Zeitung	News portals	N/A	N/A	N/A	N	N
www.tagesanzeiger.ch	Tages-Anzeiger	News portals	N/A	N/A	N/A	N	N
www.tdg.ch	Tribune de Genève	News portals	N	N/A	N/A	N/A	N
www.watson.ch	Watson	News portals	N/A	N/A	N/A	N	N
www.coopathome.ch (The original URL does not work anymore, we inspected www.coop.ch)	Coop @home	Online shops	N	N	N	N	N
www.leshop.ch	Le Shop Migros	Online shops	N	N/A	N	N	N
speedyshop.ch	It does not exist anymore	Online shops					
www.brack.ch	Brack	Online shops	N	N/A	N/A	N	N
www.conrad.ch	Conrad	Online shops	N	N/A	N/A	N	N
www.digitec.ch	Digitec	Online shops	N	Y	N	N	Y

Website	Institution/Company	Category	FR-LS	IT-LS	EN-LS	DE-LS	LS Total*
www.exlibris.ch	ex libris	Online shops	N	N/A	N/A	N	N
www.books.ch (The url redirects to: https://www.orellfuessli.ch/)	Orell Füssli	Online shops	N/A	N/A	N/A	N	N
www.weltbild.ch	Weltbild.ch	Online shops	N/A	N/A	N/A	N	N
www2.hm.com	H&M	Online shops	N	N	N/A	N	N
www.manor.ch	Manor	Online shops	N	N	N/A	N	N
www.zalando.ch	Zalando	Online shops	N	N	N/A	N	N

Note: Although the original study claimed to include 100 websites, we could only found 99 in their public report. Besides, one of the websites is included in two different categories (city and canton) and another website was no longer available when we conducted our study. Therefore, our corpus was finally made of 97 unique websites. See Bolfing 2016, Introduction.

Note: The original study included here the website of Basel city, however as this website is also analysed in the canton's category, we decided not to include it here. See Bolfing 2016, note p. 89.

** In this column the "Y" value represents that we found at least one video in one of the language variants of the website.*

Appendix B. French Corpus Analysis

Id	Web Site	Name of the Web Page	Name of the Video	Integration on web page	Integration on video platform	Integration on both	Communication methods: Sign Language	Communication methods: Oral	Communication methods: Writing	Communication methods: Captions	Thematic of the Video	Type of Video	Screen Position	Human Position
bag01	https://www.bag.admin.ch/bag/fr/home.html	Informations sur le coronavirus	Principaux modes de transmission du nouveau coronavirus	Y	Y (YouTube)	Y	LSF-SR	N	fr	fr	Health (Covid-19)	Main	Centered Top	Right
bag02		//	Qui sont les personnes particulièrement vulnérables ?	Y	Y (YouTube)	Y	LSF-SR	N	fr	fr	Health (Covid-19)	Main	Centered Top	Right
bag03		//	Utilisation correcte des masques d'hygiène	Y	Y (YouTube)	Y	LSF-SR	N	fr	fr	Health (Covid-19)	Main	Centered Middle	Right

Id	Web Site	Name of the Web Page	Name of the Video	Integration on web page	Integration on video platform	Integration on both	Communication methods: Sign Language	Communication methods: Oral	Communication methods: Writing	Communication methods: Captions	Thematic of the Video	Type of Video	Screen Position	Human Position
bag04		//	Combien de temps se passe-t-il entre l'infection et l'apparition de la maladie ?	Y	Y (YouTube)	Y	LSF-SR	N	fr	fr	Health (Covid-19)	Main	Centered Middle	Right
bag05		//	Comment se traite une infection au nouveau coronavirus ?	Y	Y (YouTube)	Y	LSF-SR	N	fr	fr	Health (Covid-19)	Main	Centered Bottom	Right
bag06		//	Recommandations pour les milieux professionnels	Y	Y (YouTube)	Y	LSF-SR	N	fr	fr	Health (Covid-19)	Main	Centered Bottom	Right

Id	Web Site	Name of the Web Page	Name of the Video	Integration on web page	Integration on video platform	Integration on both	Communication methods: Sign Language	Communication methods: Oral	Communication methods: Writing	Communication methods: Captions	Thematic of the Video	Type of Video	Screen Position	Human Position
bag07		//	Les employeurs doivent protéger les personnes vulnérables	Y	Y (YouTube)	Y	LSF-SR	N	fr	fr	Health (Covid-19)	Main	Centered Bottom	Right
bag08		//	Autres recommandations pour les milieux professionnels	Y	Y (YouTube)	Y	LSF-SR	N	fr	fr	Health (Covid-19)	Main	Centered Middle	Right
bag09		Voici les règles à suivre quand vous devez rester à la maison.	COVID-19 : Consignes sur l'isolement	Y	Y (YouTube)	Y	LSF-SR	N	fr	fr	Health (Covid-19)	Main	Centered Middle	Right
bag10		//	Utilisation correcte des masques d'hygiène	Y	Y (YouTube)	Y	LSF-SR	N	fr	fr	Health (Covid-19)	Main	Centered Middle	Right

Id	Web Site	Name of the Web Page	Name of the Video	Integration on web page	Integration on video platform	Integration on both	Communication methods: Sign Language	Communication methods: Oral	Communication methods: Writing	Communication methods: Captions	Thematic of the Video	Type of Video	Screen Position	Human Position
bag11		//	COVID-19 : Consignes sur la quarantaine	Y	Y (YouTube)	Y	LSF-SR	N	fr	fr	Health (Covid-19)	Main	Centered Bottom	Right
bag12		Informations sur le vaccin contre le COVID-19.	Vaccination contre le COVID-19 : Pourquoi dois-je me faire vacciner ?	Y	Y (YouTube)	Y	LSF-SR	N	fr	fr	Health (Covid-19)	Main	Centered Middle	Right
bag13		//	Vaccination contre le COVID-19 : Qui doit se faire vacciner ?	Y	Y (YouTube)	Y	LSF-SR	N	fr	fr	Health (Covid-19)	Main	Centered Middle	Right
chc01	https://www.ch.ch/fr/	Informations en langue des signes	Langue des signes : Qui peut voter en Suisse ?	Y	Y (YouTube)	Y	LSF-SR	fr	fr	fr	Law (Citizenship)	Main	Left Middle	Left

Id	Web Site	Name of the Web Page	Name of the Video	Integration on web page	Integration on video platform	Integration on both	Communication methods: Sign Language	Communication methods: Oral	Communication methods: Writing	Communication methods: Captions	Thematic of the Video	Type of Video	Screen Position	Human Position
chc02		//	Elections fédérales - Le Parlement suisse	Y	Y (YouTube)	Y	LSF-SR	N	fr	fr	Law (Citizenship)	Main	Right Middle	Centered
edi01	https://www.edi.admin.ch/edi/fr/home.html	Notre mandat	Vidéo en langue des signes: BFEH	Y	Y (YouTube)	Y	LSF-SR	N	fr	fr	Law (Equality)	Main	Right Middle	Right
edi02		//	Politique en faveur des personnes handicapées	Y	Y (YouTube)	Y	LSF-SR	N	fr	fr	Law (Equality)	Main	Right Middle	Centered
edi03		//	Demandes d'aides financières - Aides financières de la Confédération - BFEH	Y	Y (YouTube)	Y	LSF-SR	N	fr	fr	Law (Equality)	Main	Right Middle	Centered

Id	Web Site	Name of the Web Page	Name of the Video	Integration on web page	Integration on video platform	Integration on both	Communication methods: Sign Language	Communication methods: Oral	Communication methods: Writing	Communication methods: Captions	Thematic of the Video	Type of Video	Screen Position	Human Position
edi04		Retour en images et vidéos sur le colloque	Colloque "Participer, une chance pour toutes et tous" 3.12.2020	N	Y (YouTube)	N	LSF-SR	fr	fr	N	Law (Symposium, Equality)	Inclusive	Centered Middle	Right
uve01	www.uvek.admin.ch	Votation sur la révision de la loi sur la chasse	Langue des signes - Modification de la loi sur la chasse	N	Y (YouTube)	N	LSF-SR	fr	fr	fr	Law (Hunting)	Main	Centered Middle	Left
uve02		Initiative contre le mitage	Langue des signes - Initiative contre le mitage - votation populaire du 10 février 2019	N	Y (YouTube)	N	LSF-SR	fr	fr	fr	Law (Sprawl)	Main	Centered Middle	Left

Id	Web Site	Name of the Web Page	Name of the Video	Integration on web page	Integration on video platform	Integration on both	Communication methods: Sign Language	Communication methods: Oral	Communication methods: Writing	Communication methods: Captions	Thematic of the Video	Type of Video	Screen Position	Human Position
wbf 01	www.wbf.admin.ch	vidéos explicatives en langue des signes	Langue des signes - Prévoyance vieillesse 2020 - Votation populaire du 24. septembre 2017	N	Y (YouTube)	N	LSF-SR	fr	fr	fr	Health (Old-age provision)	Inclusive	Centered Bottom	Left
wbf 02		//	Langue des signes - Arrêté fédéral sur la sécurité alimentaire: votation populaire du 24.09.2017	N	Y (YouTube)	N	LSF-SR	fr	fr	fr	Health (Food Safety)	Inclusive	Centered Bottom	Left

Id	Web Site	Name of the Web Page	Name of the Video	Integration on web page	Integration on video platform	Integration on both	Communication methods: Sign Language	Communication methods: Oral	Communication methods: Writing	Communication methods: Captions	Thematic of the Video	Type of Video	Screen Position	Human Position
ejp01	www.ejpd.admin.ch	Vidéo avec langue des signes	Langue des signes - Modification de la directive de l'UE sur les armes	N	Y (YouTube)	N	LSF-SR	fr	fr	fr	Law (Weapon)	Inclusive	Centered Middle	Left
sbb01	www.sbb.ch	Lever les barrières pour les voyageurs sourds	Locomotive	Y	N	N	LSF-SR	N	fr	N	Public Transport (GIF, Train)	Main	Left Middle	Centered
sbb02		//	Train duplex	Y	N	N	LSF-SR	N	fr	N	Public Transport (GIF, Train)	Main	Left Middle	Centered
sbb03		//	Dérangement technique	Y	N	N	LSF-SR	N	fr	N	Public Transport (GIF, Train)	Main	Left Middle	Centered
sbb04		//	Contrôle des billets	Y	N	N	LSF-SR	N	fr	N	Public Transport (GIF, Train)	Main	Left Bottom	Centered

Id	Web Site	Name of the Web Page	Name of the Video	Integration on web page	Integration on video platform	Integration on both	Communication methods: Sign Language	Communication methods: Oral	Communication methods: Writing	Communication methods: Captions	Thematic of the Video	Type of Video	Screen Position	Human Position
sbb05		//	Bon voyage	Y	N	N	LSF-SR	N	fr	N	Public Transport (GIF, Train)	Main	Left Bottom	Centered
swi01	www.swisscom.ch	Accessibilité chez Swisscom	Vidéo Relais Swisscom pour malentendants	Y	N	N	SDGS	ge	fr	fr	Telecommunication (Video relais)	Meta-signlanguage	Centered Middle	N/A
gee01	www.ge.ch	Un nouveau site sur l'aide aux victimes réalisé par la CDAS	Aide aux victimes_Introduction	N	Y (Vimeo)	N	LSF-SR	N	fr	N	Public Service (Victim support)	Main	Centered Top	Right
gee02		//	A qui s'adresse l'aide aux victimes?	N	Y (Vimeo)	N	LSF-SR	N	fr	N	Public Service (Victim support)	Main	Centered Top	Right
gee03		//	Que fait l'aide aux victimes?	N	Y (Vimeo)	N	LSF-SR	N	fr	N	Public Service (Victim support)	Main	Centered Middle	Right

Id	Web Site	Name of the Web Page	Name of the Video	Integration on web page	Integration on video platform	Integration on both	Communication methods: Sign Language	Communication methods: Oral	Communication methods: Writing	Communication methods: Captions	Thematic of the Video	Type of Video	Screen Position	Human Position
gee04		//	Comment contacter l'aide aux victimes?	N	Y (Vimeo)	N	LSF-SR	N	fr	N	Public Service (Victim support)	Main	Centered Middle	Right
gee05		//	Gratuit, confidentiel et anonyme	N	Y (Vimeo)	N	LSF-SR	N	fr	N	Public Service (Victim support)	Main	Centered Bottom	Right
nee01	www.ne.ch	Pour une adaptation des documents officiels de l'État ... - NE.ch	Langue des signes : Initiative pour des multinationales responsables	N	Y (YouTube)	N	LSF-SR	fr	fr	fr	Law (Initiative, Multinationales responsables)	Inclusive	Left Middle	Left

Id	Web Site	Name of the Web Page	Name of the Video	Integration on web page	Integration on video platform	Integration on both	Communication methods: Sign Language	Communication methods: Oral	Communication methods: Writing	Communication methods: Captions	Thematic of the Video	Type of Video	Screen Position	Human Position
nee02		//	Langue des signes : Interdiction du financement des producteurs de matériel de guerre	N	Y (YouTube)	N	LSF-SR	fr	fr	fr	Law (Weapon)	Inclusive	Right Middle	Left
vdd01	www.vd.ch	Votation fédérale du 19 mai 2019: les enjeux	Langue des signes - Réforme fiscale et financement de l'AVS - votation du 19 mai 2019	N	Y (YouTube)	N	LSF-SR	fr	fr	fr	Law (Reform, AVS)	Inclusive	Left Middle	Left

Id	Web Site	Name of the Web Page	Name of the Video	Integration on web page	Integration on video platform	Integration on both	Communication methods: Sign Language	Communication methods: Oral	Communication methods: Writing	Communication methods: Captions	Thematic of the Video	Type of Video	Screen Position	Human Position
vdd 02		//	Langue des signes - Modification de la directive de l'UE sur les armes -	N	Y (YouTube)	N	LSF-SR	fr	fr	fr	Law (Weapon)	Inclusive	Right Middle	Left
bas0 1	https://www.unibas.ch/de	Conférences en ligne sur le droit de l'égalité des personnes handicapées	Alexia Black : Encourager une véritable désinstitutionnalisation - Une perspective de la Nouvelle-Zélande	Y	Y (SWITCHtube)	Y	LSF-SR	fr	fr	N	Law (Equality)	Inclusive	Centered Top	Right

Id	Web Site	Name of the Web Page	Name of the Video	Integration on web page	Integration on video platform	Integration on both	Communication methods: Sign Language	Communication methods: Oral	Communication methods: Writing	Communication methods: Captions	Thematic of the Video	Type of Video	Screen Position	Human Position
bas02		//	Prof. Dr. Thierry Tanquerel : Les droits politiques des personnes handicapées	Y	Y (SWITCHtube)	Y	LSF-SR	fr	fr	N	Law (Equality)	Inclusive	Centered Top	Right
bas03		//	Dr. Camilla Parker : Le droit à une vie autonome	Y	Y (SWITCHtube)	Y	LSF-SR	fr	fr	N	Law (Equality)	Inclusive	Centered Top	Right

Id	Web Site	Name of the Web Page	Name of the Video	Integration on web page	Integration on video platform	Integration on both	Communication methods: Sign Language	Communication methods: Oral	Communication methods: Writing	Communication methods: Captions	Thematic of the Video	Type of Video	Screen Position	Human Position
bas04	//	//	Dr. Caroline Hess-Klein: Stratégie en matière de litiges pour la mise en œuvre des droits des personnes handicapées	Y	Y (SWITCH-tube)	Y	LSF-SR	fr	fr	N	Law (Equality)	Inclusive	Centered Top	Left

E-Shop: no subscription access.

Biggest Cities: no video found.

Journal of Accessibility and Design for All

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

PARENTS' PERCEPTIONS OF THE IMPACT OF THE HOME ENVIRONMENT ON YOUTH LIVING WITH AN AUTISM SPECTRUM DISORDER

Alicia Ruiz-Rodrigo[1], Ernesto Morales[2], Cindy Louis-Delsoin[3], and Jacqueline Rousseau[4]

[1,3,4]School of Rehabilitation, Faculty of Medicine, Université de Montréal (Montreal), Canada; [1,3,4]Research Center, Institut Universitaire de Gériatrie de Montréal (Montreal), Canada; [1,2]Department of Rehabilitation Faculty of Medicine, Université Laval (Quebec City) Canada; [1,2]Center for Interdisciplinary Research in Rehabilitation and Social Integration (Quebec City) Canada.

[1]ORCID: *0000-0001-9761-7127*, [2] ORCID: *0000-0002-6488-5093*,

[3]ORCID: *0000-0002-4482-8315*, [4]ORCID: *0000-0001-7881-6171*

[1] alicia.ruiz-rodrigo@ulaval.ca, [2] ernesto.morales@fmed.ulaval.ca,

[3]cindy.louis@umontreal.ca, [4] jacqueline.rousseau@umontreal.ca

Received: 2021-06-18 | Accepted: 2023-02-22 | Published: 2023-05-31

***Abstract*: Background:** The prevalence of autism spectrum disorders (ASD) is estimated at 1% worldwide. People living with ASDs are often very sensitive to environmental stimuli (e.g., noise). These stimuli influence the person-environment interaction in a positive or negative way, and an excess of stimuli could cause inappropriate or unexpected behavioural responses (e.g., crisis). The Model of Competence, explaining the person-environment relationship, is the conceptual framework chosen to guide this study. The objective is to explore parents' perceptions regarding the influence of the home environment characteristics on persons living with ASD. **Methods:** A qualitative interpretive description design was used. Parents of youth with an ASD who lived in the family home until at least 16 years old participated in the study. Focus groups were conducted until data saturation. A thematic analysis was performed. **Results:** The elements impacting people living with an ASD are grouped under two themes: Non-human Environment and Human Environment. Although these elements have various effects on this population, noise, excess visual stimuli, unexpected

visitors, and changes in the environment seem to be disturbing elements. Natural light, nature, a safe environment, and stability in the environment seem to have positive effects. **Discussion:** Even though the home environment is usually a safe and stable environment, these elements emerged as fundamental. Thus, the repercussions of this in other environments that are difficult to control should be something to reflect on. **Conclusions:** Identifying these elements and their effects allows for a better understanding of the interaction between the person with ASD and their environment, both human and non-human, guiding professionals in their interventions.

Keywords: Neurodevelopment disorders, Person-Environment Interaction, Adaptation, Architectural accessibility.

Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder whose prevalence has increased significantly in recent years (Fombonne, 2003; Gouvernement du Canada, 2018). Currently, 1 in 100 people worldwide lives with an ASD (American Psychiatric Association, 2015; Howlin & Moss, 2012). In Canada, 1 in 66 children have an ASD, and for adults, the estimated prevalence is 1 in 94 (Autisme Quebec, 2019). According to the Public Health Agency of Canada (2018), ASD affects boys more often than girls. In Europe, the prevalence varies across the countries; prevalence rates varied from 1.9/10000 to 72.6/10000 (Elsabbagh et al., 2012) and from 44/10000 to 197/10000 in children aged 7-9 years (Autism Spectrum Disorders in the European Union - ASDEU, 2018). According to The British Medical Association, in October 2020, it was estimated that around 700000 people in the UK had a diagnosis of autism, and one in 100 children in the UK have a diagnosis of autism spectrum disorder (British Medical Association, 2021).

As defined in the Diagnostic and Statistical Manual of Mental Disorders - 5 (DSM-5), autism spectrum disorder is a neurodevelopmental disorder with two categories of manifestations: 1) deficits in communication skills and social interactions, and 2) restricted and repetitive behaviours, interests, or activities.

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

ASDs are sometimes associated with intellectual disability but may also be associated with language impairments and anxiety disorders (American Psychiatric Association, 2015). The manifestations of ASDs are heterogeneous and have different levels of severity. Its course over time may also vary from person to person (Charman, 2014; Nazeer & Ghaziuddin, 2012). People living with ASDs may experience difficulties in daily living activities and have significant disabilities and therefore require care and support (Organisation Mondiale de la Santé, 2019).

The quality of life of adults with ASDs is lower than the general population, and the environment could influence it (Mason et al., 2018; McConachie et al., 2018). People with ASDs may be more sensitive to sensory stimuli from the environment, including noise or excessive visual stimuli (Arnaiz Sánchez et al., 2011; Ludlow & Wilkins, 2009; Mostafa, 2008), however these, are only two examples of some of the many factors that can affect their lives such as textures, colours, type of lighting, or the shape of objects (Mostafa, 2014; Pfeiffer et al., 2017). Some elements may be regarded as offensive to the individual (e.g., noise) as may promote starting a crisis or inappropriate behaviours (Pfeiffer et al., 2005).

Hyporesponsiveness to pain (e.g., not showing signs of pain in the presence of an injury) and attempts to self-harm are common behaviours in this population, therefore environmental safety becomes particularly important (Arnaiz Sánchez et al., 2011; Mostafa, 2015; Richards et al., 2012). Several studies have shown that the behaviours of children with ASDs vary according to the context (i.e. Brown & Dunn, 2010; Kirby et al., 2017). For example, seeking sensory stimuli appears to be related to a play context, whereas hyper-responsiveness to sensory stimuli is more likely to occur during activities of daily living (e.g., covering one's ears from the sound of running water from the tap) (Kirby et al., 2017).

Most of the person-environment interaction research on ASD has been conducted on children at schools (i.e. Mostafa, 2014). However, there has been little research on the home environment of adults living with ASDs. The home environment is where the person lives and includes the human environment (e.g. parents, siblings) as well as the non-human environment (e.g. house, apartment). For the purpose of this study, residential institutions will not be included in the

concept of home environment. Since the behaviours of individuals with ASDs vary depending on the context, exploration of the home environment becomes of utmost importance. In addition, since the manifestations of ASDs persist throughout a lifetime (Organisation Mondiale de la Santé, 2019), it is necessary to identify the environmental characteristics that may affect the adults living with ASDto be able to provide more accurate interventions from health professionals. To do this, the information provided by the human environment can be very useful. Parents' perceptions are related to their experience as caregivers living in the same home as their children with ASD.

Since the environment has an impact on a person's activities and roles, this study is based on the Model of Competence (Rousseau, 2017; Rousseau et al., 2002). This model explains the interaction between the person and the environment through six concepts: person, environment (human and non-human), activities, roles, competence situation, and handicap situation. Activities and roles represent the interaction; thus, the person is situated in a continuum of competence situation or handicap situation, according to success or failure in the activities and roles. The environment can provide negative or positive stimuli to the person (Rousseau et al., 2002). In this study, the person is represented by the adult living with ASD, the human environment by other people living in the same home (e.g., parents) and the non-human environment by the physical elements of the home. Activities and roles are respectively represented by the interaction between the person and his/her non-human home environment and his/her human home environment.

The purpose of this study is to explore the parents' perceptions of youth living with ASD about the home environment characteristics (human and non-human) that influence their behaviours.

Methods

The following is a qualitative interpretive description research (Thorne, 2016) using the focus group technique (Krueger & Casey, 2015). The research questions were: 1) What are the elements of the human and non-human home environment

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

that influence the behaviour of youth with ASD? 2) How do these elements influence their activities and roles? In order to address these questions, the following sections will present 1) the participants that we recruited, 2) the data collection process, and 3) the analysis of the data.

Recruitment and participants

The selection criteria were: 1) to be a parent of a youth living with an ASD who had lived with his or her parents at least until the age of 16, and 2) to communicate in French. Only one parent per youth was included. In this way, the criteria of homogeneity (having a child living with an ASD) and heterogeneity (different families) of participants were met (Krueger & Casey, 2015).

Participants were recruited through the Association Autisme Québec, the organisation Regroupement des organismes de personnes handicapées de la région 03 (ROP-03) and social networks. Sampling is non-probabilistic, by network (snowball type) (Fortin & Gagnon, 2016).

An information document explaining the study and the eligibility criteria for participation was distributed to each organization and on Facebook groups related to ASD. The document included the contact information of the person responsible for recruitment so that interested people could reach her by email or telephone. Interested individuals were contacted by telephone to verify their eligibility and availability for the study. Once their verbal consent to participate in the study was obtained, a socio-demographic questionnaire was then sent to them by email. Finally, the consent form was signed at the time of the group meeting.

Twelve participants (n=12) were recruited and participated in the study, including ten women (83.33%) and two men. The mean age of the participants was 53.3 years. Ten participants had paid employment at the time of data collection, one participant had unpaid employment, and one participant was unemployed (see Table 1). Four participants reported that their employment relationships had been compromised because of their role as caregivers to their

children with ASD. The mean age of children of participants living with ASD at the time of the interviews was 22.9 years (see Table 2).

Table 1. Socio-demographic data of participants (parents) at the time of the interviews.

Socio-demographic variables	N	Mean (range)	%
Age (years)	12	53,3 (41-68)	
Sex - Woman	10		83,33%
Sex - Man	2		16,67%
Employment Status - Paid employment	10		83,33%
Employment Status - Unpaid employment	1		8,33%
Employment Status - Unemployed	1		8,33%
Type of accommodation - House	9		75%
Type of accommodation - Apartment	3		25%
Home adaptations	5		41,67%
No home adaptations	7		53,33%

Table 2. Socio-demographic data of participants' children at the time of the interviews.

Socio-demographic variables	N	Mean (range)	%
Age (years)	12	22,9 (18-38)	
Sex - Woman	5		41,67%
Sex - Man	7		53,33%
Employment Status - Paid employment	1		8,33%
Employment Status - Unpaid employment	1		8,33%

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

Socio-demographic variables	N	Mean (range)	%
Employment Status - Unemployed	10		83,33%
Adults with other conditions (in addition to ASD)	9		75%
Adults without other conditions (in addition to ASD)	3		25%

Data collection

Focus groups were the preferred method of data collection. The meetings took place at the <<location >> at different intervals and in the evening after work to allow parents to attend. In each session, there was a moderator and an assistant to the moderator. The moderator was a research professional and a doctoral student with experience conducting focus groups. The assistant moderator, a master's student, took notes throughout the meetings to supplement the information obtained from the recording. She presented a synthesis at the end of each meeting to validate the elements mentioned by the participants. The interview guide used by the moderator, was composed of open-ended questions and was based on the conceptual framework of the study and the recommendations of Krueger and Casey (2015), consisting on: opening, introductory, transitional, key, and final questions. Examples of key questions included: 1) Reflect on your child's behaviour at home. Could you list at least five elements of the human environment that are most influential on your child's behaviour, both positive and negative; 2) Reflect on your child's behaviour at home. Could you list at least five elements of the non-human environment that have the most influence on your child's behaviour, both positive and negative? 3) If you could build the ideal home for your child and family from the very beginning, what would it be like?

Data saturation was reached after three groups. Each group consisted of two to seven participants (Krueger & Casey, 2015; Stewart & Shamdasani, 1990): one group of seven participants and the other two groups of three and two participants, respectively. Following the first focus group, two reasons

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

influenced the choice of smaller groups: 1) the nature of the subject favoured elaborate interventions by the participants, so smaller groups allowed participants to express themselves better (Krueger & Casey, 2015; Stewart & Shamdasani, 1990); and 2) recruitment difficulties (lack of participants). Group sessions ranged in length from 130 to 146 minutes, and all meetings were recorded (audio).

Data analysis

A thematic content analysis (Miles et al., 2014) was conducted. First, the audio recording was transcribed verbatim. A list of codes, based on the concepts of the Model of Competence (Rousseau et al., 2002) and relevant elements from the scientific literature on ASD, environment, and P-E interaction, was created beforehand. Based on the data collected, two new codes were added to the list to cover content related to environmental safety and resources available to people living with ASD. The coding was validated on text extracts done separately by two authors, and an agreement of 73% was obtained. This percentage is explained by the overlap of some codes, produced by the level of specificity of the codes (general codes including more specific ones).

The transcripts were coded using Nvivo software (QSR International, 2018). Subsequently, data reduction was performed in three phases (R1-R2-R3), depending on the codes. This reduction allowed the identification of themes and sub-themes (Creswell, 2014; Miles et al., 2014). For example, during the first reduction phase (R1), a table was created with the first code of some extracts of the verbatim. Then after discussing the associations of the different codes with the research team, some of the extracts of verbatim were moved to another more relevant new code. All four authors of this manuscript participated actively in all the reduction steps.

Ethical approval was obtained from the rehabilitation and social inclusion sectorial research committee of the Centre intégré universitaire de santé et de services sociaux— Capitale-Nationale (#2017-554).

Results

The results answer the two research questions: 1) What are the elements of the human and non-human home environment that influence the behaviour of youth with ASD? 2) How do these elements influence their activities and roles? The results are grouped under two main themes: 1) the non-human environment and 2) the human environment.

NON-HUMAN ENVIRONMENT

Under this theme, there are two categories of elements: 1) sensory, and 2) related to the coherence and the security of the environment.

Sensory elements

All these elements include visual, sound, olfactory, tactile and proprioceptive stimuli. However, the visual and sound stimuli stand out, as they are the ones most discussed by the participants.

Visual and sound stimuli

Participants considered that certain elements of the non-human environment can have a sensory overload effect. For example, bright colours would be disruptive. "[In his room]: a yellow then a blue with a stripe of cars for children. It was very stimulating there. The yellow one was more like mustard, ... It was beautiful, but he didn't have a good night' sleep." (P010)

In addition, cluttered spaces also appear to be a problem for adults with ASDs who prefer clean, functional spaces. For this reason, purely decorative elements do not seem to be adequate since they may overstimulate them. Discomfort, fatigue, and anxiety often appear in adults with ASDs when they are in an environment with too many visual stimuli. For example, too many colours in the same room or a crowded environment: "It has to be tidy because if there are too many things in the visual environment, it stimulates the brain too much." (P005).

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

All participants noted that sounds have a significant impact on people living with ASDs. Noises of various kinds (e.g., loud and shrill, continuous, noise from appliances or compressors, screams) are disturbing to them, causing, in some cases, a handicap situation. One participant mentioned:

> The noise of the fridge, the noise of the appliances... That is our big problem, (...) she turns off her fridge and almost turns off her heating in winter. That's why I don't want her to stay alone, she can't cook herself, since she doesn't have a fridge because of the noise. So, it takes a structure where there is really no noise: the fridge away. (P005)

In response to excessive noise, people living with ASDs sometimes adopt maladjusted strategies; isolation appears to be one of the most common. Other strategies are adaptations of activities and roles (person-environment interaction) to facilitate their success. For example, one participant reports that his child chooses his work schedule based on days when there is less noise.

Participants describe some elements of the environment as having a calming effect on their children, such as pale colours. For light, natural light was described as having a very positive effect, except for one participant who mentioned that natural light seemed to be disturbing for his child. One participant explained:

> Daylighting certainly makes a big difference. (...) We saw a big difference because in our old house (...), was very dark, and now we're in a condo with floor-to-ceiling windows; I saw a really big [positive] difference in behaviour. (P012)

However, too much light seemed disturbing for the children of all participants. A rotating light (a lamp that spins around itself and makes the light beams rotate) is described as calming and may promote sleep for some people with ASD.

The music seems to have a positive calming effect on several of the participants' children, and quiet and noise-free environments promote a sense of comfort.

Olfactory and tactile stimuli

Although they are less prominent in the results, four participants mentioned that certain olfactory stimuli (e.g., strong food odours when cooking) have a negative effect on their children. Related to tactile stimuli, soft textures seem to have a positive effect, while rough or pungent textures seem to have a disturbing effect (e.g., food, fabrics).

Finally, some proprioceptive stimuli, such as pressure on the body, seem to have a calming effect:

> I use a lizard (Manimo weighted stuffed lizard) that weighs twelve pounds to calm him down. When we see that he is anxious at home, (...) I put it on his shoulders (...) It's a weighing (...). It's calming. It's a bit like the big coat that weighs a lot. There is one in the house: he takes shelter with it. (P010)

Regarding nature, four participants describe it as a calming place for their children, even promoting communication.

> We did a lot of *canoe-camping* in northern Quebec (...), you're not full of stimuli, I found it was a completely different person. The calmer it is, the more they are in nature, the more they can focus on a beautiful communication, an exchange, not a monologue. (P012)

Coherence and safety in the non-human environment

Participants granted particular importance to the coherence of the elements integrated in an environment. For example, a panel that is not the same colour as the wall can be disturbing. Some environments seem to promote some activities; for example, the arrangement of furniture that creates a feeling of being surrounded can promote sleep. Storage space and filing systems seem significant for people living with ASDs. Each person seems to have their own different, consistent filing systems. Visual cueing of objects seems to help them. One participant explained that about his daughter. "It's really all filed, (...) she

knows where she puts her stuff, I don't do her housework anymore, because there was a fight about that. She has a place for everything" (P011).

Still related to coherence, stability (absence of change) in the non-human environment was emphasized by participants. Anxiety can arise when the environment presents changes or elements that are beyond the person's control.

> She doesn't want things to be moved around, she doesn't like to change the furniture, the decoration, the painting (...). We must keep the colour codes. If you want to paint so that she doesn't cry, you put the same colour back on. (P009)

The issue of safety is often raised by participants. Sharp, electrical, hot, or broken items can be dangerous for people living with ASDs. For example, some participants explained that broken items are disruptive, and their children will sometimes damage them even more by trying to remove what is already broken. Several participants noted that anything can become dangerous and highlighted the importance of safe environments: "When I say she is self-harming, she is much less sensitive to pain than we are, so she can stick a pencil or fork in herself; [if she is] in crisis, anything can become dangerous to her." (P003)

According to participants, under certain circumstances, these individuals may act abruptly:

> In our house, it is a marble countertop and then the sink is glued underneath. He leans so hard when he washes that he took off the sink; when we realized that it was leaking under the sink, my boyfriend says "yes, it wasn't done "*autistic-proof*". It takes solid but effective things. (P012)

The use of resistant materials would be adequate for the environment of people living with ASD, while still being comfortable.

Sometimes people living with ASDs may engage in risky behaviours, putting themselves or others at risk. Some risk behaviours are self-harm (e.g., related to sensation-seeking and hyposensitivity to pain) or destruction of the environment when disturbing elements are presented (e.g., broken clothing, pictures, or

items). One participant reported: “She likes to brush her hair a lot, she’ll even tear it out.” (P003). Participants identify adaptations to the non-human environment to alleviate safety-related difficulties. Another participant mentioned: “The whole house is adapted. We have no choice. And when I adapted, it’s not because it’s sophisticated, it’s mostly it’s safe all the way through.” (P004)

HUMAN ENVIRONMENT

The elements identified under this theme are the stability of the human environment, communication and technology.

Stability of the human environment

Regarding the stability and predictability of the human environment, most participants agree on the importance of routines and schedules for their children. Routines seem to support the functioning of people living with ASDs and changes become problematic, which can cause anxiety. One participant report “My son, just that I’m 5 minutes late, it can provoke a lot, a lot of anger to him.” (P006).

People living with ASDs often require adjustment from their human environment or need verbal or physical support to carry out their activities and roles. Several participants explained that they must constantly adjust to the needs of their children in terms of routines and schedules. One participant explained: “You shouldn’t rush him at any time, you really must adapt to his speed, his routine. At the end of the day, in our case, we live for him. We adapt to his time, his speed, his routine.” (P010)

Sometimes people living with ASDs can adopt maladjusted strategies when exposed to stimuli that are negative for them. On one hand, they may isolate themselves when there are many people or strangers, or in emotionally complex situations (e.g., conflict). Also related to the stability of the environment, participants in all focus groups spoke of visitors as being very disruptive to their children living with ASD, especially if the visit was not planned. Similarly, strangers can become an anxiety-provoking element. One participant said: “She doesn’t like visitors in the house, except for her sister. But there are people in

the family, like her grandparents, she says she feels they disturb her routine." (P009)

On the other hand, having a trusted person seems to be helpful for people living with ASDs. It allows them to confide in someone and to ask for help or support when needed, promoting a sense of security. According to participants, this role is often assumed by one of the parents, if the person lives in the family home.

Communication and technology

Participants discussed their children's relationships. Participants perceive relationships with other people with ASDs (homogeneity with the human environment) to be easier than with other people, such as neurotypical people or people with intellectual disabilities. Some indicate that in a residential setting, a place exclusive to people with ASDs must be favoured.

> You don't mix person with autism with a person with an intellectual disability. My son has a girlfriend that's been three years old, (...) she's intellectually disabled. (...) When she's tired, instead of saying, "Well, leave me alone," she says, "Not friends anymore, I don't love you anymore, go away, you're getting on my nerves...". And he, well, he's having an epileptic seizure. (...) The trick here is to put autistic people with autistic people, that's the winning formula. (P006)

Another element described as disruptive is the judgment towards people living with ASDs. Sometimes aggression may appear in situations where the person does not feel understood by those around him or her. As one participant said:

> I think it's important that people have a good perception of the phenomenon rather than categorizing it as a disease that needs to be cured. There is no cure for autism. You are autistic, you live with autism and you die with autism. (P014)

Finally, technology, such as a cell phone or computer, appears to be a supportive and positive communication element for some people living with ASDs, often used

as an adaptive strategy to avoid interactions. However, many participants identify difficulties in their children when communicating by telephone:

> She prefers in person or online [rather than on the phone]. Through *chat* or networks, Facebook, whatever, she's perfectly at ease. (...) She doesn't even want to make the appointment over the phone. She says, "Mom, I don't know what to say! If the person asks me questions, I get confused, I have too much stuff in my head at the same time, I'm not able to structure what I have to say." (P014)

On a different stream of thought, participants explained that elements such as acceptance of ASDs, coping skills, expectations, repetitive or stereotypical behaviours, hypo- and hypersensitivity, or digestive disorders also appear to have an impact on the activities and roles of people living with ASDs.

Overall, the results showed that elements are perceived as having a positive (Table 3) or negative (Table 4) effect on people living with ASD, depending on the type of stimuli and the individual's preferences. Thus, the impact of the same item may have a different effect on different individuals. These tables are not intended to establish causal links, but rather to provide examples of items that parents perceive to have an impact on the lives of their children living with an ASD.

Table 3. Examples of environmental elements perceived to have a positive effect on people living with ASD. (a) Non-human environment.

Element (what)			**Effect (how)**
Visual	Colour	Pales	Calm
Visual	Light	Natural	Calm
Visual		Rotating	Favouring sleep
Auditive	Music		Calm
Proprioceptive	Weighing	Soothing	Positive, but no effect has been described
Proprioceptive	Compression garments		Positive, but no effect has been described

Element (what)		Effect (how)
Storage space	Customized filing systems	Favouring competency situation
Storage space	Visual cueing of objects	Favouring competency situation
Resistant materials		Favouring competency situation
Stability		Sense of security, comfort
Cleanliness	Clean environment	Comfort
Object / personal space		Positive, but no effect has been described
Nature		Calm, encouraging communication

Table 3. Examples of environmental elements perceived to have a positive effect on people living with ASD. (b) Human environment.

Element (what)		Effect (how)
Homogeneity	People living with ASD	Encouraging communication
Judgments	Feeling understood	Positive, but no effect has been described
Trusted Person		Sense of security, request for support
Communication	Technology	Competence situation, favouring communication
Stability	Routine	Favouring the competency situation

Table 4. Examples of environmental elements perceived to have a negative effect on people living with ASD. (a) Non-human environment.

Element (what)			Effect (how)
Visual	Colour	Bright	Sleep disturbance, fatigue
Visual	Light	Excess light	Negative, but no effect has been described
Visual	Shape and pattern	Mosaic	Overcharge

Element (what)			Effect (how)
Visual	Congested environment		Fatigue, over-stimulation, anxiety
Auditive	Noise	Appliances	Anxiety, handicap situation
Auditive	Noise	Alarm, screams	Anxiety, discomfort, isolation
Olfactory	Strong smells (kitchen)		Negative, but no effect has been described
Tactile	Texture	Viscous (Food)	Handicap situation
Tactile	Texture	Rough (Textile)	Negative, but no effect has been described
Sharp, hot objects, electrical			Injury/self-injury
Broken elements			Discomfort, destructive behaviour
Changes			Anxiety
Cleanliness	Germs		Anxiety
Decorative elements			Over-stimulation

Table 4. Examples of environmental elements perceived to have a negative effect on people living with ASD. (b) Human environment.

Element (what)		Effect (how)
Heterogeneity	*Neurotypical* persons, other disabilities	Negative, but no effect has been described
Judgments	Feeling of incomprehension	Anxiety, aggressiveness
Judgments	Ignorance of ASD	Negative, but no effect has been described
Too many people		Anxiety, isolation
Visit	Planned	Discomfort
Visit	Not foreseen	Discomfort / Anxiety
Unknown		Anxiety, isolation
Communication	Emotionally complex situation	Isolation
Communication	Phone	Anxiety, handicap situation
Stability	Changes	Anxiety, inappropriate strategies

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

Discussion

The purpose of this study was to explore the elements of the environment that affect the relationship between the person living with an ASD and his or her environment and the effect that these elements may have on the person. Many elements of the environment were identified by participants as having an impact on the activities and roles of their children living with ASDs that persist into adulthood. These elements and their impact, however, vary from person to person, meaning that the same element of the environment may have a different impact on each person or even the opposite effect. Thus, environmental interventions become a challenge, especially in an environment shared by several people, such as the living, working, and school environment. This challenge is related to the heterogeneity of ASDs profiles. Individuals living with ASDs may present a variety of manifestations in terms of their nature, severity, and progression (American Psychiatric Association, 2015; Charman, 2014; Fountain et al., 2012; Nazeer & Ghaziuddin, 2012).

This heterogeneity of manifestations related to ASD, as demonstrated in our results, is more related to the non-human environment, particularly for sensory elements. The idiosyncratic nature of environmental preferences is present in all persons, however, this appears to be more accentuated in people with ASDs (American Psychiatric Association, 2015). However, despite this heterogeneity, some elements that emerged in our results seem to be repeated in a larger number of people with ASD. These elements are noise, visual stimuli, safety, environmental stability, and control.

In our results, we found that one of the most common elements was noise, which could cause, according to the participants, discomfort, anxiety or even disability. These results are in line with the work of Landon and his collaborators (2016). Several types of noise were mentioned by the participants in our study as disturbing: noise from household appliances, continuous noise (e.g. machinery) and sudden noise (e.g. car alarm). Kanakri et al. (2017) also identified several types of potentially disturbing noises, including air conditioning and traffic noise, which are similar to those identified by our participants. Other authors like

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

Arnaiz-Sánchez and colleagues (2011) and Mostafa (2008), identify noise as one of the elements to be considered in the design of environments for individuals with ASD because of the influence it can have on this population.

Regarding visual stimuli, we mainly found elements related to the lights and the colours in this study. Participants explained that natural light could be pleasant for their children and have a positive effect on their behaviour, conversely, to too much artificial light which could have a disturbing effect. Again, this goes in the same stream of thought as other studies that have also identified the excess of light as an element that can disturb people living with ASD (Pfeiffer et al., 2017; Stewart et al., 2016). For colours, our participants mentioned that their children tend to prefer pale or pastel colours over brighter colours which could be disruptive. Grandgeorge and Masataka (2016) suggest similar results in their study: children living with ASD had a preference for green and brown colours and the least preferred colour is yellow because it has a higher brightness value.

Concerning safety, we found that hyperreactivity to pain and temperature related to sensation-seeking may lead the person to use some objects to stimulate or even injure themselves. However, Richards et al. (2012) demonstrate that persons living with ASD and self-injurious behaviours had higher levels of hyperactivity and impulsivity and lower capacity to express themselves. Also, some people's awareness of danger is affected and may compromise their safety. As a result, sharp, electrical or hot items can put people at risk. Our results are consistent with those reported by Boyle et al. (2014), which describe the safety of children with ASD as a major concern for their parents.

The notion of stability is present in our findings both in the human and non-human environment, consistent with some characteristics that are common in people living with ASDs. According to Poljac et al. (2017), one of these characteristics seems to be their low adaptive capacity. This characteristic can be translated in having limitations in tolerating change and instability in the environment (human and non-human) and may interfere with person-environment interaction. According to the Model of Competence (Rousseau, 2017; Rousseau et al., 2002), the person is considered as an open system. The person and the environment are in constant interaction and there is a mutual

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

influence between them. A low adaptive capacity can therefore disrupt this interaction and, consequently, the competence of developing activities and assuming roles. The home is, in principle, a safe and stable environment, unlike others such as school or public spaces, so it is worth noting that elements such as security and stability emerged in our results. This can lead us to reflect on and imagine of the significant proportions, in terms of stability and security, of the other environments in which an autistic person interacts.

The notion of control also seems to be present in this population. Many of the elements discussed in our study suggest that situations beyond the control of the person living with ASD may be problematic. Some of these elements include changes in plans, routines or schedules, unannounced visits, changes in decor, layout, or storage space. These are generally described as having negative effects on the person living with an ASD.

Our results indicate that in some situations, it is not just the environmental stimuli that disrupt activities and roles, but rather stimuli combined with the typical characteristics of ASD. Pfeiffer et al. (2017) report similar findings in their study of the environment of young children with ASDs. For example, regarding the interpretation of the information provided by the environment, adults living with ASDs appear to have a limited ability to select this information and distinguish between what is most and least important. Therefore, when the non-human environment presents many stimuli simultaneously, the person may experience fatigue or a behavioural crisis. Regarding the human environment, an emotional overloading situation may be difficult to manage due to low social skills, thus, the person may tend to isolate.

Strengths and Limitations

The results obtained in this study represent the parents' perceptions of the impact of the environment on their children living with ASDs. There is a limitation associated with the choice of the design research, and the results cannot replace a standardized assessment of the environment of people living with ASDs.

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

Some strengths of the study support its credibility. On the one hand, the data were validated with the participants at the end of each focus group meeting, in accordance with this technique (Krueger & Casey, 2015). On the other hand, all the analyses were carried out by the research team and authors of this paper, to ensure rigour and minimize the bias associated with concordance during coding validation extracts done separately by two of the authors. The choice of moderator was also a strength of the study, due to his experience in group facilitation and his neutral role in the study (he is not a co-author of this article), thus minimizing the risk of bias during data collection. The validation of the coding was carried out on text extracts done separately by two of the authors and in agreement.

The main limitation concerns the transferability of the data; due to the diversity of the study population, a larger sample would have favoured transferability. Another limitation is related to coding validation (agreement=73%). This limitation is related to the structure of the code list which includes general codes that encompass specific codes. Also, this limitation is related to the difference in expertise between the two co-authors who performed the coding validation (occupational therapy and design) and the length of the text chosen for validation. A longer text could have resulted in a better percentage of agreement. This potential bias was minimized by including the four authors during the entire analysis process.

Conclusions

The identification of elements of the environment and their effects provides a better understanding of the interaction between the persons living with ASD and their environment, both human and non-human. The elements of the environment that have an impact on people with ASD are very heterogeneous, but several elements, such as sensory stimuli or changes in the environment, are recurrent. As mentioned before, the home environment is of vital importance for every individual. It is of most relevance the understanding of the feelings attached to this particular space, such as security and control, for the autistic person to live fully. Therefore, professionals involved in adapting the home

environment for people with ASD (e.g. occupational therapists) should assess the interaction between the person and his or her environment to identify the appropriate environmental elements and features for each person. The results of this study can guide professionals in their interventions with this population. However, more research needs to be done in order to better understand the person-environment interaction in the living environment and to provide tools for professionals.

Acknowledgments

The authors would like to thank the Office des personnes handicapées du Québec for funding the study (grant #N/D2231) and the Faculty of Medicine and the School of Rehabilitation of Université de Montréal for the scholarships awarded to the first author of the article.

Conflict of Interest

The authors have no conflicts of interest in connection with this study.

References

[1] American Psychiatric Association. (2015). *DSM-5 : manuel diagnostique et statistique des troubles mentaux* (J. D. Guelfi & M.-A. Crocq, Trans.; 5th ed.). Issy-les-Moulineaux : Elsevier Masson.

[2] Arnaiz Sánchez, P., Segado Vázquez, F., & Albaladejo Serrano, L. (2011). Autism and the Built Environment. In Intech (Ed.), *Autism Spectrum Disorders - From Genes to Environment* (pp. 364-380). Intech.

[3] Autism Spectrum Disorders in the European Union (ASDEU). (2018). *Executive summary 12/09/2018*. http://asdeu.eu/wp-content/uploads/2016/12/ASDEUExecSummary27September2018.pdf

[4] Autisme Quebec. (2019). *L'autisme en chiffres*. http://www.autisme.qc.ca/tsa/lautisme-en-chiffres.html

[5] Boyle, P., Haines, D., Lovelock, L., & Innes, K. (2014). Home Safety for Children with Autistic Spectrum Disorder: Local Authority Occupational Therapy

Intervention. *British Journal of Occupational Therapy*, *77*(5), 243-250. https://doi.org/10.4276/030802214x13990455043485

[6] British Medical Association. (2021). *Autism spectrum disorder*. Retrieved 19/04/2021 from https://www.bma.org.uk/what-we-do/population-health/child-health/autism-spectrum-disorder

[7] Brown, N. B., & Dunn, W. (2010). Relationship between context and sensory processing in children with autism. *American Journal of Occupational Therapy*, *64*(3), 474-483. https://doi.org/10.5014/ajot.2010.09077

[8] Charman, T. (2014). Variability in neurodevelopmental disorders. Evidence from Autism Spectrum Disorders. In J. V. Herwegen & D. Riby (Eds.), *Neurodevelopmental Disorders. Research challenges and solutions* (pp. 117-140). Psychology Press.

[9] Creswell, J. W. (2014). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches* (4 ed.). SAGE Publications.

[10] Elsabbagh, M., Divan, G., Koh, Y.-J., Kim, Y. S., Kauchali, S., Marcín, C., Montiel-Nava, C., Patel, V., Paula, C. S., Wang, C., Yasamy, M. T., & Fombonne, E. (2012). Global Prevalence of Autism and Other Pervasive Developmental Disorders. *5*(3), 160-179. https://doi.org/https://doi.org/10.1002/aur.239

[11] Fombonne, E. (2003). Epidemiological Surveys of Autism and Other Pervasive Developmental Disorders: An Update. *Journal of Autism and Developmental Disorders*, *33*(4), 365-382. https://doi.org/10.1023/a:1025054610557

[12] Fortin, M.-F., & Gagnon, J. (2016). *Fondements et étapes du processus de recherche : Méthodes quantitatives et qualitatives* (3 ed.). Chenelière Éducation.

[13] Fountain, C., Winter, A. S., & Bearman, P. S. (2012). Six developmental trajectories characterize children with autism. *Pediatrics*, *129*(5), e1112-1120. https://doi.org/10.1542/peds.2011-1601

[14] Gouvernement du Canada. (2018). *Trouble du Spectre De L'autisme chez les enfants et les adolescents au Canada 2018*. https://www.canada.ca/fr/sante-publique/services/publications/maladies-et-affections/trouble-spectre-autisme-enfants-adolescents-canada-2018.html#a2-2

[15] Grandgeorge, M., & Masataka, N. (2016). Atypical Color Preference in Children with Autism Spectrum Disorder. *Frontiers in Psychology*, *7*, 1-5, Article 1976. https://doi.org/10.3389/fpsyg.2016.01976

[16] Howlin, P., & Moss, P. (2012). Adults with autism spectrum disorders. *The Canadian Journal of Psychiatry*, *57*(5), 275–283.

[17] Kanakri, S. M., Shepley, M., Varni, J. W., & Tassinary, L. G. (2017). Noise and autism spectrum disorder in children: An exploratory survey. *Research in Developmental Disabilities*, *63*, 85-94. https://doi.org/10.1016/j.ridd.2017.02.004

[18] Kirby, A. V., Boyd, B. A., Williams, K. L., Faldowski, R. A., & Baranek, G. T. (2017). Sensory and repetitive behaviors among children with autism spectrum disorder at home. *Autism*, *21*(2), 142-154. https://doi.org/10.1177/1362361316632710

[19] Krueger, R. A., & Casey, M. A. (2015). *Focus Groups : A Practical Guide for Applied Research* (5th ed.). SAGE

[20] Landon, J., Shepherd, D., & Lodhia, V. (2016). A qualitative study of noise sensitivity in adults with autism spectrum disorder. *Research in Autism Spectrum Disorders*, *32*, 43-52. https://doi.org/10.1016/j.rasd.2016.08.005

[21] Ludlow, A. K., & Wilkins, A. J. (2009). Case report: Color as a therapeutic intervention. *Journal of Autism and Developmental Disorders*, *39*(5), 815-818. https://doi.org/10.1007/s10803-008-0672-5

[22] Mason, D., McConachie, H., Garland, D., Petrou, A., Rodgers, J., & Parr, J. R. (2018). Predictors of quality of life for autistic adults. *Autism Research*, *11*(8), 1138-1147. https://doi.org/10.1002/aur.1965

[23] McConachie, H., Mason, D., Parr, J. R., Garland, D., Wilson, C., & Rodgers, J. (2018). Enhancing the Validity of a Quality of Life Measure for Autistic People. *Journal of Autism and Developmental Disorders*, *48*(5), 1596-1611. https://doi.org/10.1007/s10803-017-3402-z

[24] Miles, M. B., Huberman, M., & Saldana, J. (2014). *Qualitative data analysis: A methods sourcebook* (3rd ed.). SAGE. https://us.sagepub.com/en-us/nam/qualitative-data-analysis/book239534

[25] Mostafa, M. (2008). An architecture for autism: concepts of design intervention for the autistic user. *ArchNet - IJAR: International journal of architectural research*, *2*(1), 189-211. http://search.ebscohost.com/login.aspx?direct=true&db=bvh&AN=612560&lang=fr&site=ehost-live

[26] Mostafa, M. (2014). Architecture for autism: autism ASPECTSS (TM) in school design. *ArchNet - IJAR: International journal of architectural research*, *8*(1),

143-158. http://search.ebscohost.com/login.aspx?direct=true&db=bvh&AN=713892&lang=fr&site=ehost-live

[27] Mostafa, M. (2015). Architecture for autism: Built environment performance in accordance to the autism ASPECTSSS design index. *Design Principles and Practices: An International Journal 8*.

[28] Nazeer, A., & Ghaziuddin, M. (2012). Autism spectrum disorders: clinical features and diagnosis. *Pediatr Clin North Am*, *59*(1), 19-25. https://doi.org/10.1016/j.pcl.2011.10.007

[29] Organisation Mondiale de la Santé. (2019). *Datos y cifras. Transtorno del espectro autista.* https://www.who.int/es/news-room/fact-sheets/detail/autism-spectrum-disorders

[30] Pfeiffer, B., Coster, W., Snethen, G., Derstine, M., Piller, A., & Tucker, C. (2017). Caregivers' Perspectives on the Sensory Environment and Participation in Daily Activities of Children With Autism Spectrum Disorder. *American Journal of Occupational Therapy*, *71*(4). https://doi.org/10.5014/ajot.2017.021360

[31] Pfeiffer, B., Kinnealey, M., Reed, C., & Herzberg, G. (2005). Sensory Modulation and Affective Disorders in Children and Adolescents With Asperger's Disorder. *American Journal of Occupational Therapy*, *59*(3), 335-345.

[32] Poljac, E., Hoofs, V., Princen, M. M., & Poljac, E. (2017). Understanding Behavioural Rigidity in Autism Spectrum Conditions: The Role of Intentional Control. *Journal of Autism and Developmental Disorders*, *47*(3), 714-727. https://doi.org/10.1007/s10803-016-3010-3

[33] QSR International. (2018). *NVivo*. In (Version 12)

[34] Richards, C., Oliver, C., Nelson, L., & Moss, J. (2012). Self-injurious behaviour in individuals with autism spectrum disorder and intellectual disability. *Journal of Intellectual Disability Research*, *56*(5), 476-489. https://doi.org/doi:10.1111/j.1365-2788.2012.01537.x

[35] Rousseau, J. (2017). Modèles généraux en ergothérapie: Le Modèle de compétence. In M.-C. Morel-Bracq (Ed.), *Les modèles conceptuels en ergothérapie-Introduction aux concepts fondamentaux* (2 ed., pp. 107-119). De Boeck Supérieur.

[36] Rousseau, J., Potvin, L., Dutil, E., & Falta, P. (2002). Model of Competence: A Conceptual Framework for Understanding the Person-Environment Interaction

for Persons with Motor Disabilities. *Occupational Therapy in Health Care*, *16*(1), 15-36. https://doi.org/doi:10.1080/J003v16n01_02

[37] Stewart, C. R., Sanchez, S. S., Grenesko, E. L., Brown, C. M., Chen, C. P., Keehn, B., Velasquez, F., Lincoln, A. J., & Muller, R. A. (2016). Sensory Symptoms and Processing of Nonverbal Auditory and Visual Stimuli in Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *46*(5), 1590-1601. https://doi.org/10.1007/s10803-015-2367-z

[38] Stewart, D. W., & Shamdasani, P. N. (1990). *Focus Group. Theory and Practice* (Vol. 20). SAGE Publications.

[39] Thorne, S. E. (2016). *Interpretive description : qualitative research for applied practice* (2 ed.). Routledge - Taylor & Francis. http://public.eblib.com/choice/publicfullrecord.aspx?p=4511832

Journal of Accessibility and Design for All

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

VISUAL-SENSORY-BASED QUIET ROOM: A STUDY OF VISUAL COMFORT, LIGHTING, AND SAFE SPACE IN REDUCING MALADAPTIVE BEHAVIOUR AND EMOTION FOR AUTISTIC USERS

Annisa Marwati[1], Ova Candra Dewi[2], Tjhin Wiguna[3], and Aisyah[4]

[1, 2, 4] Department of Architecture, Faculty of Engineering, Universitas Indonesia, Depok, Indonesia

[3]Department of Psychiatry, Faculty of Medicine, Universitas Indonesia, Jakarta, Indonesia

[2]ORCID: 0000-0001-5418-3146, [3]ORCID: 0000-0002-7524-5868,

[4]ORCID: 0000-0002-4199-4799

[2]ova.candewi@ui.ac.id

Received: 2021-02-01 | Accepted: 2023-05-02 | Published: 2023-05-31

Abstract: This study investigates strategies for developing visual sensory-based quiet rooms for individuals with autism spectrum disorders to reduce maladaptive behaviours and emotions. Optimizing visual sensory comfort in a quiet room is expected to help a person relieve the maladaptive behaviours and emotions that he/she is experiencing. This laboratory-based case study was conducted through a literature review and case studies in two quiet rooms in a school as the laboratory observation. Both schools provide special education services and an inclusive education school. This study aims to provide a reference for creating spaces for autistic individuals in supporting a more inclusive and sustainable environment. A total of eight respondents (four students from each school), aged between 7-21 years old, were involved in this study. Data for the analysis was obtained by observing the physical conditions of the existing quiet room and assessing the respondents' behaviour and emotions while they were inside the room. The behaviour and emotion assessments were based on 12 active behaviours and emotions on the Aberrant Behavior Checklist - Irritability (ABC-I) instrument. Meanwhile, lighting simulations were also conducted using the software DIALux evo 8.1 to determine the rooms' lighting situation. The case studies showed that (1) most of the respondents showed response related to the

quiet room's visual comfort; (2) the respondents in a quiet room with less lighting contrast intensity were more likely to experience a decrease in maladaptive behaviour and emotion; and (3) one of the respondents gave more response in auditory stimulation, which showed that non-visual sensory stimulation should also be put into consideration for a quiet room design. It was concluded that visual stimulation in a quiet room might affect the users' maladaptive behaviour or emotional change. Therefore, a visual-sensory-based intervention for a quiet room potentially increases its effectiveness.

Keywords: quiet room, maladaptive behaviour, and emotions, autism spectrum disorders, visual sensory, visual comfort, quiet room needs, quiet room security.

Introduction

Autism Spectrum Disorder Syndrome, or widely known as Autism Spectrum Disorder (ASD), is a neurodevelopmental disorder characterized by several unusual behaviours (Ismail, W, Wiguna, & Kaligis, 2018). According to Gillberg & Coleman (2000), ASD is a disorder in the part of the brain that regulates a person's ability to communicate and interact socially (Barakat, Bakr, & El-sayad, 2019). Currently, cases of individuals with ASD are widespread in the world. The estimated prevalence of autism spectrum disorder cases globally is 62/10,000 or approximately 1:160 of the world's population (Elsabbagh, et al., 2012). There is no definite statistical data available in Indonesia, but it is estimated that the number of autism spectrum disorder cases in Indonesia reaches 2.4 million cases out of a total of 237.5 million people, or a ratio of 1:100 individuals (The Ministry of Women Empowerment and the Child Protection Republic of Indonesia, 2018). Thus, the importance of discussing issues about individuals with autism spectrum disorders is vital, including those relating to their needs for space.

ASD is closely related to Sensory Processing Disorder (SPD), which is a term to describe someone's inability to effectively utilize sensory information in daily function (Kranowitz, 2005). A certain degree of SPD suffered by an autistic individual may affect spatial experiences and trigger responses in the form of disruptive or maladaptive behaviours and emotions. The earlier study stated that about 69% -93% of individuals with autism spectrum disorders, both children and adults, have sensory issues (McCormick, Hepburn, Young, & Rogers, 2016). The

sensory hypersensitivity of autistic individuals makes them more sensitive to the small details around them (Baron-Cohen, Ashwin, Ashwin, Tavassoli, & Chakrabarti, 2009). Moreover, Baker et al. (2008) found a consistent and moderate to strong correlation between sensory processing difficulties and the presence of maladaptive behaviour (Lane, Young, Baker, & Angley, 2010). Maladaptive behaviours are behaviours that interfere with everyday activities, including self-injurious behaviour, withdrawal, uncooperative, aggression, damaging objects, and even the increasing of negative emotions (Shattuck, et al., 2006; Samson, Hardan, Lee, Phillips, & Gross, 2015). The level of sensory stimulation in a room for an autistic individual may determine its space comfort and affect the presence of maladaptive behaviour and negative emotion.

Among all the sensory comforts that someone can feel, the provision of visual comfort in a room may have more effect on how an autistic person perceives a space. This is supported by the fact that at least 80% of the information received by the brain is obtained from eye-sensory visual input (Kranowitz, 2005). Also, individuals with autism spectrum disorders generally learn something from their visual senses (Shabha & Gaines, 2013). The important role of visual input shows that visual sensory concept for a quiet room potentially brings a more considerable effect to gain space comfort, which may lead to a lower level of maladaptive behaviours and emotions. Therefore, the developed quiet room interventions in this study were primarily based on the visual comfort consideration, while comfort issues were taken as supporting considerations.

This study discusses visual-sensory-based spatial intervention strategies for a quiet room to help autistic users relieve their maladaptive behaviour and emotion. The purpose of this study is to investigate possible interventions that may work in gaining a comfortable space for a quiet room and reducing disturbing behaviour and emotion. The results of this research are expected to be a reference for further study and development of architectural spaces for autistic users.

Methodology

This study is a laboratory-based case study and was carried out with a qualitative approach. It started with literature studies and continued with case studies in

two quiet rooms as the laboratory observation. Each quiet room was in two different types of schools; a special education school and an inclusive school (from now on referred to as the Special School A and the Inclusive School B). The selection of these two types of schools is aimed at obtaining more diverse profiles of respondents since autistic students in inclusive schools are more likely to be able to sit still for long periods, can follow the rules, can understand instructions, and control emotions (Ekawati & Wandansari, 2012). The case studies include (1) profiling the existing quiet room, and (2) observing the interaction between the respondents and the quiet room including by doing assessments and online interviews. The overall data obtained from the case studies and theories regarding spaces for autistic users were analyzed and elaborated to formulate a proposed intervention for a quiet room, according to the needs of the existing space.

The respondents who participated in this study were students aged 7-21 years who used the school's quiet room to deal with the maladaptive behaviour and emotion they experienced. The activities of the respondents in the quiet room were observed by (1) assessing changes in behaviour or emotion before the respondent entered the quiet room and during their presence in the room and (2) observing and analyzing the interaction between the respondents and the quiet room from the spatial context. The Closed-Circuit Television (C.C.T.V.) cameras were installed to obtain the supporting data needed, followed by an online interview with the teacher as the assessor.

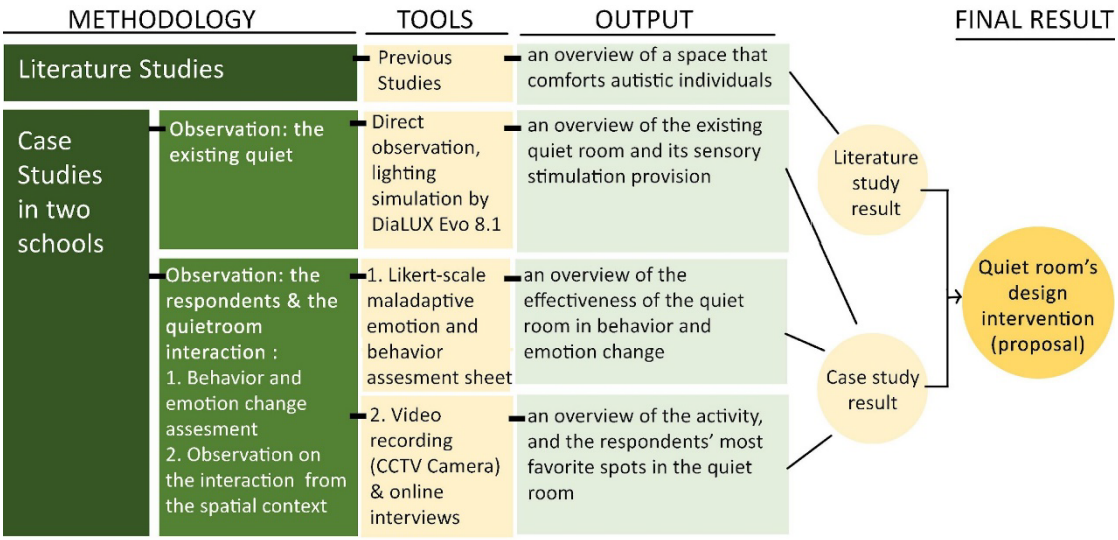
Assessment of behaviour and emotional change was done within a 5 minute range until the respondent could leave the quiet room. The assessment was carried out by the respondents' teacher, as the teacher was more familiar with the respondent's daily behaviour and more competent in recognizing the unusual behaviour shown by the respondents. A Maladaptive Emotion and Behaviour Assessment Sheet with a Likert Scale was used as the assessment tool. This tool was arranged based on the active behaviours or emotions listed on the Aberrant Behavior Checklist - Irritability (ABC-I) instrument. The ABC-I instrument is widely known for measuring behaviour problems in individuals with developmental disorders, including autism spectrum disorder (Brinkley, et al., 2007; Kaat, Lecavaller, & Aman, 2014). Moreover, further behavioural observation was done with the support of video recording. The use of video technology offers

advantages in assessing complex behaviours, although it could be intrusive as it may alter the naturally occurring behaviours (Haidet, Tate, Divirgilio-Thomas, Kolanowski, & Happ, 2009). Therefore, the camera was placed high enough so it could be as idle as possible to the respondents. However, according to Latvala, Vuokila-Oikkonen, & Janhonen (2000), video recording may provide incomplete real-time situation and lack of important contextual data (Haidet, Tate, Divirgilio-Thomas, Kolanowski, & Happ, 2009). For that reason, online interviews with each of the respondents' teachers (who also did the maladaptive and behaviour assessment) were carried out to get a clearer contextual image of what happened inside the quiet room.

The case study, including the lighting intensity simulation, was analyzed by the DIALux evo 8.1 lighting simulation software to obtain data from the spatial context. The simulation was not aimed to get the nominal value of lighting levels in the quiet room but rather to help determine the spread of light inside the room instead.

The literature and case studies results were then analyzed and elaborated to formulate appropriate design interventions for each school (See Figure 1). The formulation of the intervention was subsequently translated into an image of a proposed quiet room design intervention. This laboratory-based case study was the initial research for the development of a visual-sensory-based quiet room, and it has not been tested for a wider range of autistic users.

Figure 1. Methodology flow.



Results

Literature Studies

A visual-sensory-based quiet room is developed based on three parameters, namely visual comfort for autistic users, quiet room's calming function, and safety (Marwati, Dewi, & Wiguna, 2020). Thus, the following literature study will mainly discuss the strategies of the three parameters that make a visual-sensory-based quiet room.

Visual Comfort for Autistic Users

Differences in perceptions of individuals with autism spectrum disorders should be seen as a unique perspective of the dimensions of space and time rather than as a disability (Ahlquist, 2015). For this reason, in presenting a visual-sensory-based quiet room, it is important to understand the perspective of individuals with autism spectrum disorders in perceiving space visually, including their view on the suitability of lighting. There are four factors of the suitability of lighting: colour, lighting atmosphere and colour, light direction, and glare level (Szokolay, 2004). The following paragraphs will mainly discuss the three keywords in these factors: colour, lighting, and glare.

For a space that is intended for autistic individuals, it is recommended that the colours chosen should be muted (low-saturated) colours. Disturbing and overly stimulating colours should be avoided (Altenmüller-Lewis, 2017). Furthermore, colours that create a safe, comfortable, and soothing ambience are the colour of green or blue (Mahnke & Mahnke, 1993; O'Connor, 2011). Thus, the suggested colour for the quiet room is muted colours. Meanwhile, blue and green may give a more calming atmosphere to the room.

The next keyword to the suitability of lighting is the lighting itself. Based on its sources, at least there are two kinds of lighting, which are natural lighting and artificial lighting. Natural lighting brings many benefits to individuals with autism spectrum disorders (Altenmüller-Lewis, 2017). However, the use of natural lighting must be controlled to avoid excessive contrast and glare. For artificial lighting, it is not recommended to use fluorescent lamps since autistic individuals usually have high sensitivity to flickering light (Altenmüller-Lewis, 2017). LED

lighting is recommended as it is also more energy efficient (Szokolay, 2004). Moreover, warm colour temperature lamps are likeable for autistic individuals' rooms (Long, 2010). Artificial lighting should also be equipped with a dimmable system to adjust the light intensity as needed (Altenmüller-Lewis, 2017). Therefore, adjustable LED lights with less flickering effect and a warm-colour temperature are preferred.

For the lighting glare, it should be kept as minimum as possible. Glare can be avoided by using an artificial light diffuser, indirect lighting design, shades, openings/windows at both low- and high-level allocation, non-reflective materials, and maintaining enough distance from the centre of vision to the lighting source (Lechner, 2015; Mostafa, 2008; Ghazali, Md. Sakip, & Samsuddin , 2018). It should be noted that careful control of reflections, glare, and shadow pattern is also necessary (Altenmüller-Lewis, 2017).

Supporting the calming function of a Quiet Room

Quiet Room is one of the facilities needed within the education establishment for individuals with autism spectrum disorders (Mostafa, 2014; Altenmüller-Lewis, 2017; Ghazali, Md. Sakip, & Samsuddin, 2018). A quiet room or also referred to as an "Escape Space," is defined as a space that is intended as a 'resting' space for autistic students who experience excessive stimulation (Altenmüller-Lewis, 2017; Mostafa, 2008). Another study defines a quiet room as a space that provides a calm effect when students are experiencing behavioural disturbances caused by fatigue, stress, or excessive stimulation (Ghazali, Md. Sakip, & Samsuddin, 2018). This space can be a partitioned area or a space to crawl in a room (Mostafa, 2014). Moreover, a quiet room should have minimal distraction and stimulation, and it may also be equipped with sensory stimulation, which can be adjusted according to the stimulation intensity needed, either for stimulation or for a calming effect (Altenmüller-Lewis, 2017). For this reason, it is possible to equip a quiet room with items that have sensory stimulation, such as pillows with different textures, brushes, small tents, blankets, etc. (Mostafa, 2014). Stimulation-based zoning of space should be provided. The zoning consideration should include whether it is for hypersensitive or hyposensitive individuals. Quiet rooms should be separated acoustically (Ghazali, Md. Sakip, & Samsuddin, 2018). It needs to have a quiet

room to reduce distraction and sensory discomfort for children with autism spectrum disorders. Moreover, there is no definite standard dimension for this room, but the size of the quiet room should not be too big or too small, considering that room size can be a factor of fear in children with autism spectrum disorders (Mayes, et al., 2013).

Safety

The safety aspect is also essential in a quiet room because the behaviour of individuals with autism spectrum disorders can be difficult to predict. A Quiet room must not provide a chance for someone to endanger himself/herself (Ghazali, Md. Sakip, & Samsuddin, 2018), especially if he/she is behaving aggressively. However, it is important always to note that safety is considered the most critical aspect of spatial planning for individuals with autism spectrum disorders (Altenmüller-Lewis, 2017).

Case Studies Results

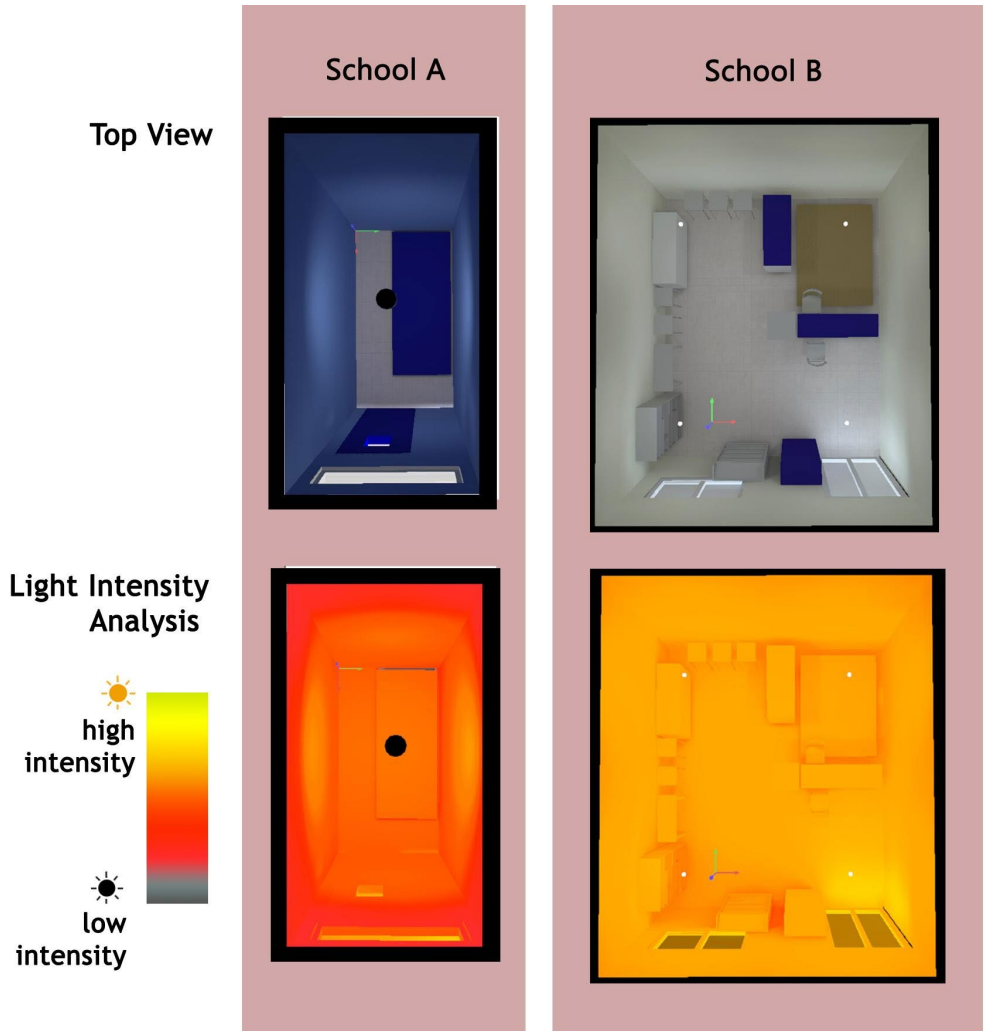
School A, a school with a special education service, has two quiet rooms called quiet room 1 and quiet room 2. In this study, only one of the quiet rooms which highly aggressive students frequently use will be observed, namely quiet room 1. Quiet room 1 has a size of 1.58 x 2.9 m and a ceiling height of 3 meters which serves as a space to cool off. In contrast to quiet room 2, which has a bed, quiet room 1 only has a mattress as a comfortable area for students who need to calm down.

In terms of lighting, Quiet Room 1 relies on artificial lighting from a single point of light and indirect natural lighting. The electric lamp is a downlight-stick lamp with a cool colour temperature light (6500 K). The lighting glare from electronic lamps is minimized with the use of downlight luminaire. In this room, there is no direct natural light source, but natural light from the nearest window can slightly enter the room through the reflection of the surrounding surfaces. The light glare is hardly found in this room.

At School B, the Inclusive School, there is no dedicated quiet room for autistic students, but there is a room with a similar function. This room has an area of 30 m^2 with a length on each side of 6 m and 5 m, respectively. The height of the

room ceiling is 3 meters. This room has many functions related to educational service activities for students with special needs, including a temporary quiet room for children who show disruptive behaviour during school hours. The room is equipped with various kinds of furniture, such as carpets, cupboards, gym balls, tables, and other therapeutic equipment. In using the room, the teachers accompany students with maladaptive behaviours and emotions. In terms of lighting, the existing quiet room has direct natural light sources in the form of sandblast-finished glass doors and windows. Natural light can enter the room directly because the corridor to this room is semi-open. The artificial lighting installed in the room is four cool-coloured temperature stick lamps.

Figure 2. Light intensity simulation analysis using DIALux evo 8.1 software at School A (Left) and School B (Right)



Based on the lighting simulation by the DIALux evo 8.1, it is known that the spread of lights in the existing School A's quiet room is perfectly even; no area looks

much lighter or darker (See Figure 2 - Left). Meanwhile, the quiet room at School B has the most contrast light intensity, and the area with the lowest light intensity is covered with a carpet (See Figure 2 - Right).

The interaction between the respondents with the existing quiet room

During the interaction between the respondents and the existing quiet room, an assessment of the behaviour and maladaptive emotional changes was performed by analyzing it along with its spatial aspect analysis. The assessments were based on 12 active behaviours and emotions on the Aberrant Behavior Checklist - Irritability (ABC-I) instrument. The behaviours and emotions assessed at this stage are coded with the M1 – M12 code, as listed in Table 1.

Table 1. List of observed behaviours and emotions. (a) Non-verbal behaviour.

Behaviour (Non-Verbal)	**Code**
Excessively active at home, school, work, etc.	M1
Meaningless recurring body movements	M2
Abnormal repetitive movements	M3
Aggressive to other children or adults	M4
Injures self on purpose	M5
Impulsive (Acts without thinking)	M6

Table 1. List of observed behaviours and emotions. (b) Verbal behaviour.

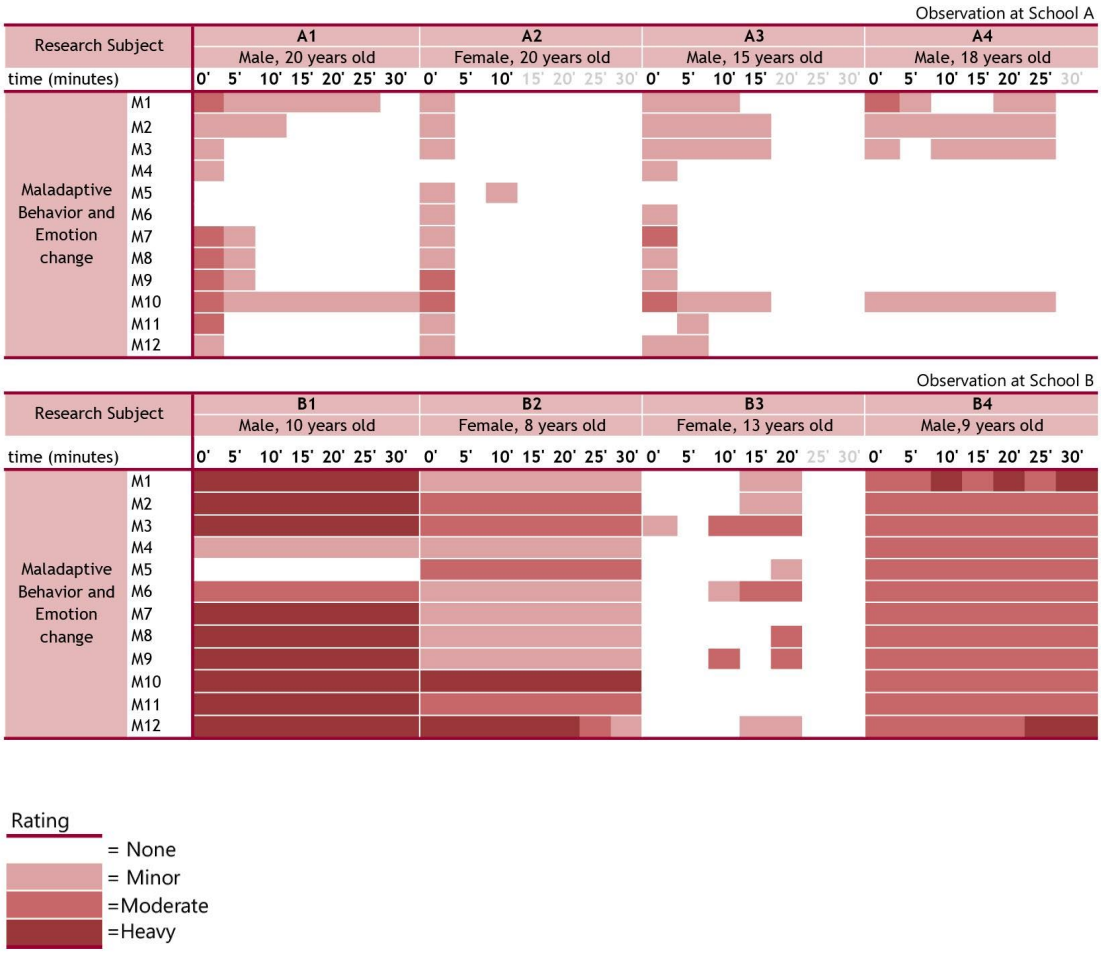
Behavior (Verbal)	**Code**
Screams inappropriately	M7
Talks excessively	M8
Boisterous (inappropriately noisy or rough)	M9

Table1.List of observed behaviours and emotions. (c) Emotions.

Emotion	**Code**
Restless, unable to sit still	M10
Irritable and Whiny	M11
Temper tantrums	M12

The observation and assessment of two different quiet rooms showed various behavioural responses. Behavioural and emotional problems that frequently surfaced were excessively active, meaningless body movement, abnormal repetitive movement, and restlessness, unable to sit still. Graphs of changes in behaviour and emotions that occurred while in the existing quiet room can be seen in Figure 3.

Figure 3. Graphs of changes in behaviour and emotions before and during entering the existing quiet room at School A & School B.



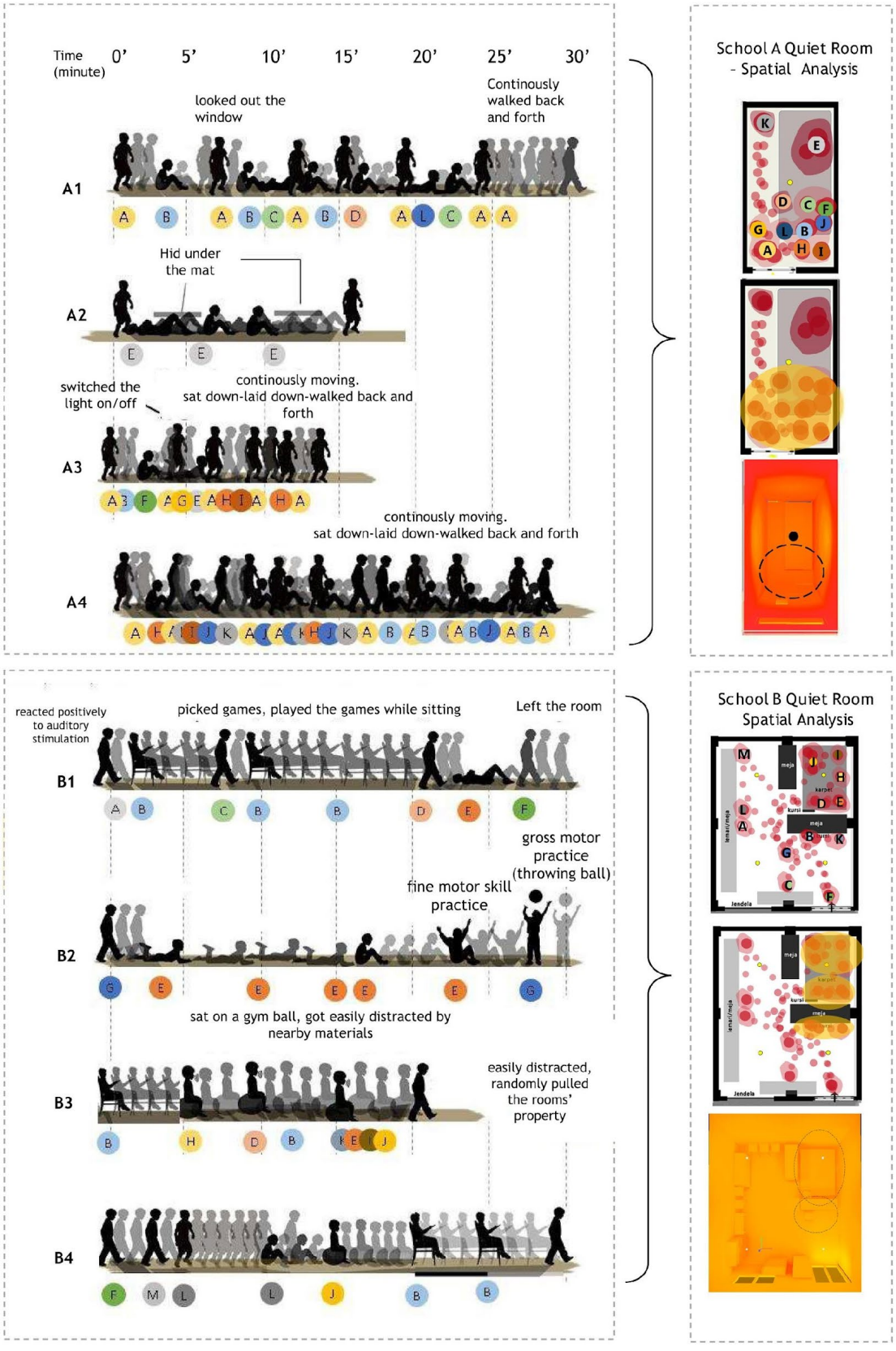
At School A, four subjects joined as the respondents, further referred to as A1, A2, A3, and A4. From the observations, the maladaptive behaviours and emotions had decreased since the 5th minute and gradually decreased after that (See Figure 3). At School B, four subjects also used the existing quiet room, further referred to as B1, B2, B3, and B4. During their stay in the existing quiet room, the respondents were accompanied by each of their shadow teachers. From the assessment results, it appears that not all subjects experienced a decrease in maladaptive behaviour and emotions. Subject B1 did not experience changes in behaviour and emotions even after 30 minutes, B2 experienced a decrease, while B3 and B4 experienced an increase in behavioural and emotional problems.

Based on this assessment, it can be concluded that only one subject at School B experienced a decrease in maladaptive emotional and behavioural problems during their entry into the existing quiet room. Meanwhile, the other two subjects had more problems, and the other one did not experience any changes.

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

Moreover, almost all respondents at School A showed interaction related to visual comfort. A1, A3, and A4 often looked out of the room through the door openings when standing at point A (See Figure 4 – top right box). In contrast, A2 covered her body with a mattress during the 5th and 10th minutes while calming herself down. While this behaviour might show that A2 needed proprioceptive input, there was also a possibility that she might need to reduce the visual stimulation she received by hiding under the mat. However, this situation was a hint that non-visual sensory stimulation was also important to be available in a quiet room. Furthermore, A3 repeatedly pressed the room light switch button in the 5th minute as if he wanted to control the light intensity of the room (see Figure 4 – top right box).

Figure 4. Spatial Analysis of Respondents' Interactions in the Existing Quiet Room of School A, and School B.



Overall, the most occupied area in the room was the one close to the door, near the opening that provides natural lighting with an outside view (See Figure 4 – top right box). The variety of behaviours associated with visual stimulation showed that each subject had different stimulation needs. However, this stimulation need cannot be defined specifically because each subject showed different behaviour according to their respective needs.

Meanwhile, the situation in School B's quiet room was slightly different. While entering the room, students at Inclusive School B walked to several sides of the room, sat down, or rocked on the gym ball, and also sat and lay down on the carpet. Several other activities, such as playing games and motoric skill activities, were carried out with guidance from the teacher (See Figure 4 – bottom left box).

The behaviour related to visual comfort was shown by B4, preferring the room's lights to be turned on. Moreover, for B3, too many objects in the room caused a distraction. One of the respondents seemed to enjoy more auditory sensory stimulations to calm down. Once again, this showed that the availability of non-visual sensory stimulation should also be put into consideration.

For the spatial pattern analysis, there were two areas that were favoured by the respondents. One of these favoured areas was the one with a closed, bordered area that formed a separate space in the existing room. According to the simulation, this area received the least light in the entire room. Another frequently visited area was the one near the table with seating. What these two areas had in common is that they both had a separate space limitation from the placement of the furniture in the room (See Figure 4-bottom right box). A more detailed spatial analysis regarding the interaction of research subjects with the existing quiet room can be seen in Figure 4.

From the case studies, at least three points can be concluded; (1) most of the respondents showed a response in terms of the quiet room's visual comfort. This showed that visual stimulation in a room might have a certain effect on behaviour and emotional change while using a quiet room. However, each subject had different stimulation needs; (2) the respondents in a quiet room with less lighting contrast intensity were more likely to experience a decrease in maladaptive behaviour and emotion; (3) two of the respondents showed responses that could

be related to proprioception and auditory stimulation respectively, which showed that for a quiet room design, non-visual sensory stimulation should be put into consideration.

Discussion

This section mainly discusses the possible visual-sensory-based design intervention that can be implemented in both existing quiet rooms. The intervention discussed also put forward the efficiency value by minimizing unnecessary interventions and optimizing the existing conditions that can be maintained. The design intervention was carried out by elaborating the results of case studies with previous theoretical reviews.

Intervention Design for the Visual Comfort

One concept in a visual-sensory-based quiet room is the optimization of visual comfort in that space. The proposed design interventions that need to be carried out in the existing quiet rooms at Schools A and B are as follows:

- Replace existing lamps with LED lamps with warm colour temperatures (2700-300K) so they are comfortable for the child's visual senses. This is in line with several theories that say that warm temperature and soft-white-golden lights are recommended for rooms for individuals with autism spectrum disorders (Long, 2010; Kinnealey, et al., 2012). Meanwhile, this type of LED lamp is recommended as it is more energy-efficient than other types of lamps (Szokolay, 2004).

- Provide dimmable controls that allow children to adjust the brightness of the light. Dimmer control provides an opportunity for individuals with autism spectrum disorders to self-regulate the light intensity they need to receive (Altenmüller-Lewis, 2017).

- Room lamps are installed with downlight housings and equipped with light diffusers. In addition to avoiding glare, the diffuser also functions to reduce bright lights (Lechner, 2015).

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

- Arrange the room so it is not exposed to direct light sources to minimize glare. Of the two rooms, the quiet room at School B potentially causes glare. In this case, the proposed design intervention is to create a separate quiet space with clear boundaries within the room.

- Covering the floor with a non-reflective material.

- Gives an atmosphere of soothing blue and green colours that give a calm atmosphere. In this case, the blue colour, which has now become the colour of the walls in School A's quiet room, is proposed to be applied to the B School quiet room. Green artificial lighting is added to give the room a greenish-blue atmosphere. This light can be deactivated so that one can choose whether to add green to the room or not. This artificial lighting will be designed with an indirect lighting system that is planted in a wall higher than the eye level (180 cm) and covered with acrylic to avoid glare.

Intervention Design to Support Calming Function of the Quiet Room

A visual-sensory-based quiet room is not only concerned with the aspect of visual comfort. Quiet rooms must still meet the needs of space as a resting space for individuals with autism spectrum disorders who are experiencing maladaptive emotions and behaviours. In the proposed design interventions for School A & B quiet rooms, the proposed design interventions are as follows:

- Provide an area with minimal stimulation in the form of a tent. This proposal is based on the theory that an escape space may be in a form of crawling (Mostafa, 2014). This tent also acts as a space with minimal stimulation for hypersensitive children who require it.

- Only provide minimal numbers of furniture or items to minimize distraction. This is mainly in response to the behaviour of one of the respondents who was easily distracted.

- Separate the quiet room from rooms with other functions. Apart from reducing light contrast and intensity from the door area, this is also proposed based on the consideration that quiet rooms should be acoustically separated from other rooms (Ghazali, Md. Sakip, &

Samsuddin, 2018). This point is also related to the recommendation that rooms in schools for students with autism spectrum disorders should have clear boundaries in terms of function and sensory quality so that the users can easily recognize the use of these spaces (Ghazali, Md. Sakip, & Samsuddin, 2018).

- Equip the quiet room with items that can provide sensory stimulation safely (other than visual stimulation), such as pillows with different textures.

- Adjust the room size so that it is neither too small nor too large to anticipate the fear in children with autism spectrum disorders. In this case, the size of the quiet room at School A cannot be changed because the change in size will affect the construction of other rooms around it, so it will be less efficient. Hence, this step can only be done in the quiet room proposed at School B. The proposed size of the room is 2 m x 2.5 m with a fixed ceiling height of 3 meters. This is suggested so that the room is not too large and too small and does not interfere with the existing room's functions.

Intervention Design for Room Safety

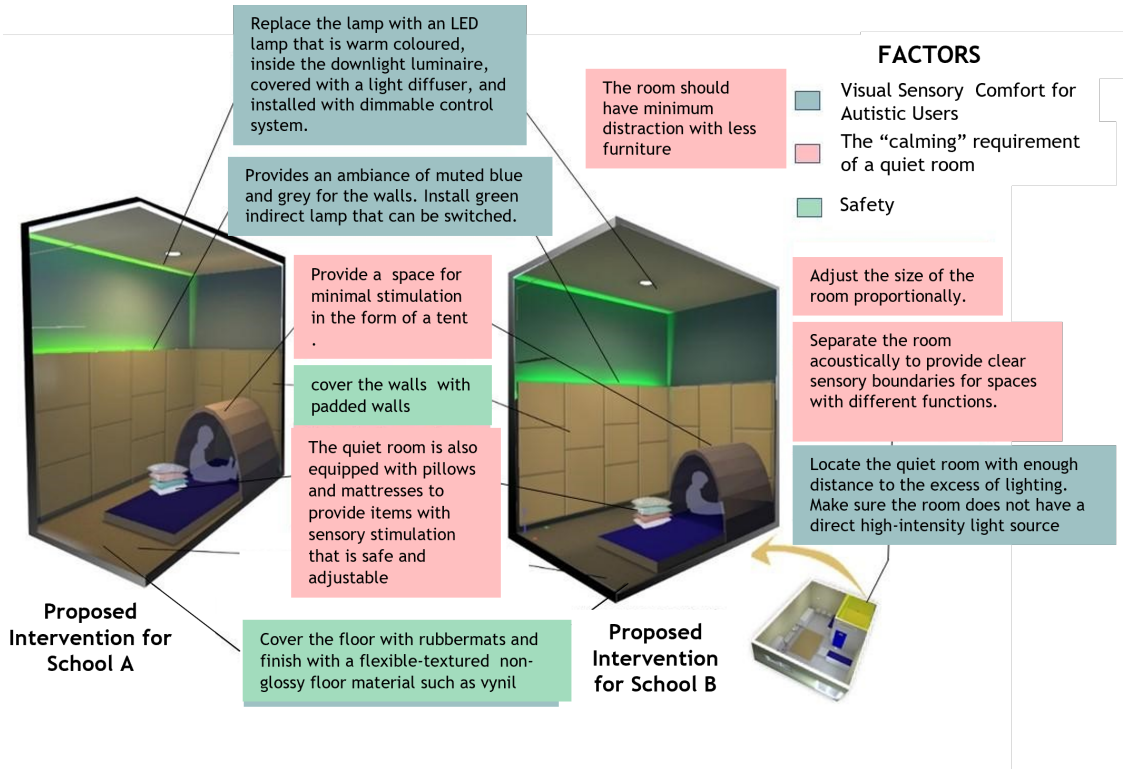
The quiet room proposed in this study is a quiet room that autistic users can use with minimum assistance from other people. For this reason, the quiet room must be equipped with safe materials to anticipate aggressive behaviour, which can lead to injury. Suggestions in the safety aspect are as follows:

- Cover the walls with padded walls. The addition of this material aims to make the walls less hard and risky when the user is aggressively hitting his/her body against the wall.

- The floor area is covered with a rubber mat so that its surface becomes softer and more flexible. The rubber mat floor can eventually be finished with a non-reflective material.

Based on the previous description, an illustration of the proposed visual-sensory-based quiet room is shown in Figure 5.

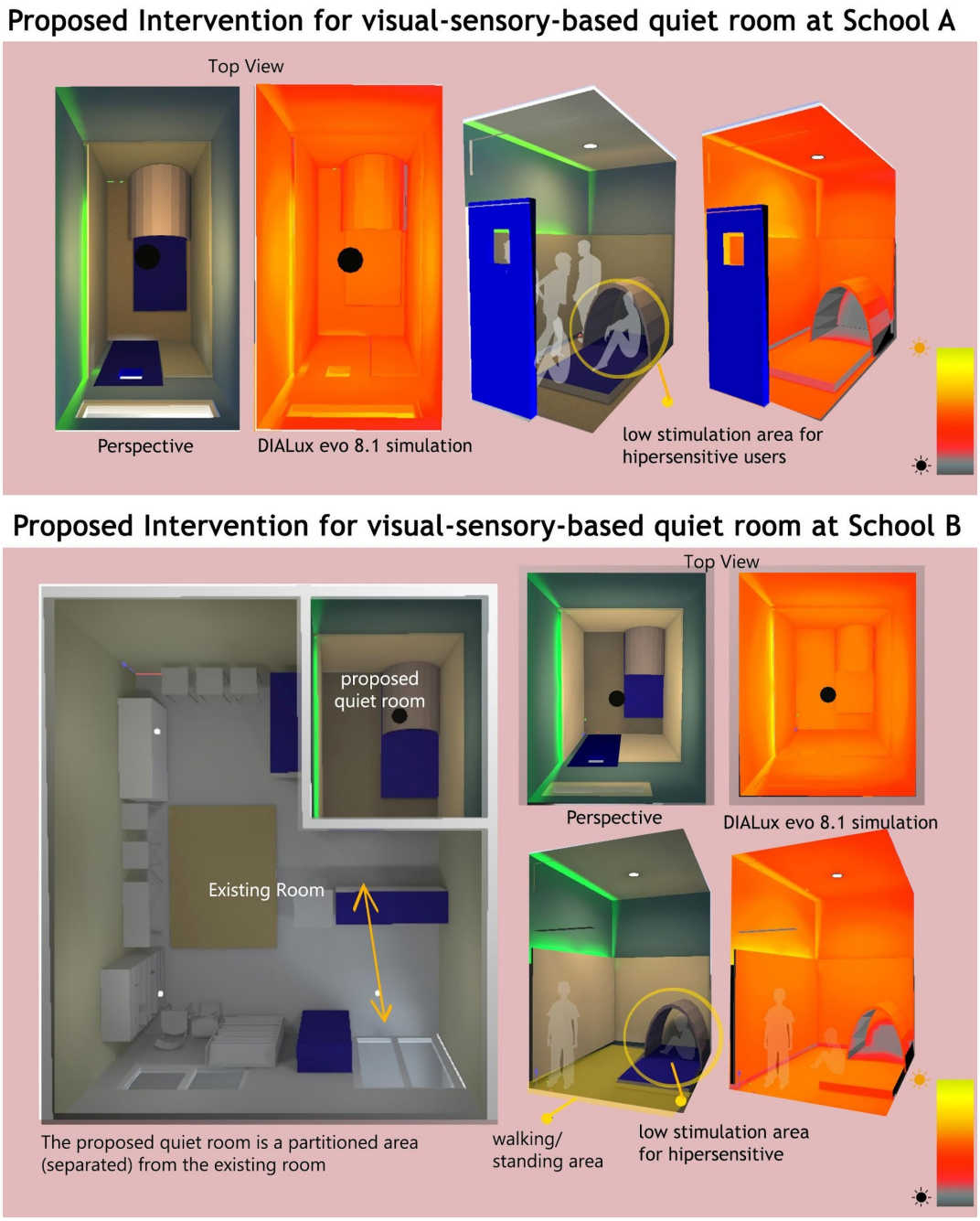
Figure 5. Illustration of Proposed Visual-Sensory-Based Quiet Room.



The results of lighting analysis with DIALux evo 8.1 software (Figure 6) in the proposed room showed that the proposed intervention design has less light contrast intensity. However, the tent in the room provides more variety of sensory stimulation zones, and it can be used by individuals who need minimal stimulation.

At the Inclusive School B (picture at the bottom), it can also be seen that separating the quiet room from the existing room simultaneously reduces the intensity of excess light that enters the quiet room.

Figure 6.Lighting analysis on the proposed Visual Sensory-Based Quiet Room for School A (top) and School B (bottom) .



Conclusion

The study shows that visual stimulation can affect a person's behaviour in a quiet room. Considering most of the case studies' conclusions are related to visual stimulation, a visual-sensory-based intervention for a quiet room may make a quiet room more effective in decreasing maladaptive behaviour and emotion. Moreover, a visual-sensory-based quiet room means an escape space that (1) has

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

lighting with a warm colour temperature, free from glare, and a calming character colour atmosphere, (2) does not have excessive sensory stimulation, especially for non-visual stimulation, (3) is separated, and has different sensory stimulation level compared to other rooms around it, (4) has sensory stimulation that can be controlled and/or adjusted to each of the users' sensory needs to calm down, and (5) responds to the possibility of unexpected dangerous behaviour that may occur. This concept can also be embedded in any room with a similar relaxing function, such as a multisensory room, although some adaptations should be carefully considered to support the actual or other function of the room.

This research explored the use of the existing quiet room in each school and attempted to provide design intervention proposals based on the available theory and data. However, until now, no research has proven the effectiveness of visual-sensory-based quiet rooms in relieving maladaptive behaviour and emotion. In this case, it is necessary to carry out further experimental research to obtain an evaluation of the proposed design intervention.

Evaluation can be done in the form of research regarding (1) the light intensity for individuals with autism spectrum disorders, (2) the latest available lighting technology used for the development of this quiet room, and (3) the light setting preference of autistic individuals in a quiet room.

Additionally, further research can be carried out regarding the findings that the subjects of child age tend to experience higher behavioural and emotional problems than adolescents and adults. These findings reveal opportunities for tracing the (1) hypersensitivity comparisons of individuals with autism spectrum disorders at different age groups, (2) recommendations on the importance of assistance and supervision for younger users in a quiet room, and (3) the needs of different quiet room formulation for each lifespan. The intervention strategy in this research can be adjusted and implemented in any room intended for autistic users. The existence of quiet rooms in public spaces can provide more inclusive space for individuals with autism spectrum disorders. It is hoped that this may bring more autistic individuals' involvement in society.

Acknowledgment

This research is part of a project entitled “Visual-Sensory-Based Quiet Room for Autistic Children” which is funded by Directorate of Innovation and Science Techno Park Universitas Indonesia (DISTP-UI) through the Prototype Planning Funding Program 2020 (Hibah Kompetisi Program Pendanaan Perancangan Pengembangan Purwarupa Tahun 2020) No. PKS-120/UN2.INV/HKP.05/2020.

References

[1] Ahlquist, S. (2015). Social sensory architectures: Articulating textile hybrid structures for multi-sensory responsiveness and collaborative play. ACADIA 2015 - Computational Ecologies: Design in the Anthropocene: Proceedings of the 35th Annual Conference of the Association for Computer Aided Design in Architecture.

[2] Altenmüller-Lewis, U. (2017). Designing Schools for Students on the Spectrum. The Design Journal, 20(sup1), S2215-S2229.

[3] Barakat, H. A., Bakr , A. F., & El-sayad, Z. (2019). Nature as a Healer for Autistic Children. Environmental Science and Sustainable Development.

[4] Baron-Cohen, S., Ashwin, E., Ashwin, C., Tavassoli, T., & Chakrabarti, B. (2009). Talent in autism: hyper-systemizing, hyper-attention to detail and sensory hypersensitivity. Philosophical Transactions of the Royal Society, 1377-1883. doi:10.1098/rstb.2008.0337

[5] Brinkley, J., Nations, L., Abramson, R. K., Hall, A., Wright, H. H., Gabriels, R., . . . Cuccaron, M. L. (2007). Factor Analysis of the Aberrant Behavior Checklist in Individuals with Autism Spectrum Disorders. Journal of Autism and Developmental Disorders, 1949-1959.

[6] Ekawati, Y., & Wandansari, Y. Y. (2012). Perkembangan Interaksi Sosial Anak Autis di Sekolah Inklusi : Ditinjau dari Perspektif Ibu. Experientia Jurnal Psikologi Indonesia, 1(1). Retrieved from http://journal.wima.ac.id/index.php/EXPERIENTIA/article/view/48/46

[7] Elsabbagh, M., Divan, G., Koh, Y.-J., Kim, Y. S., Kauchali, S., Marcin, C., . . . Fombonne, E. (2012). Global Prevalence of Autism and Other Pervasive Developmental Disorders. Wiley Autism Research, 160-179.

[8] Ghazali, R., Md. Sakip, S. R., & Samsuddin , I. (2018). The Effects of Sensory Design on Autistic Children. Asian Journal of Behavioural Studies, 3(14), 68.

[9] Ghazali, R., Md. Sakip, S. R., & Samsuddin, I. (2018). A Review of Sensory Design Physical Learning Environment for Autism Centre in Malaysia. Environment-Behaviour Proceedings Journal, 3(7).

[10] Haidet, K. K., Tate, J., Divirgilio-Thomas, D., Kolanowski, A., & Happ, M. B. (2009). Methods to Improve Reliability of Video-Recorded Behavioral Data. Research in Nursing & Health, 465–474.

[11] Henry, C. N. (2011, October 19). Designing for Autism: Lighting. (ArchDaily) Retrieved November 29, 2019, from https://www.archdaily.com/177293/designing-for-autism-lighting

[12] Houser, K., Mossman, M., Smet, K., & Whitehead, L. (2016). Tutorial: Color Rendering and Its Applications in Lighting. The journal of the Illuminating Engineering Society of North America, 7-26.

[13] Ismail, R. I., W, N. S., Wiguna, T., & Kaligis, F. (2018). Buku Panduan : Deteksi Dini, Diagnosis dan Tata Laksana Gangguan Spektrum Autisme. Jakarta: Badan Penerbit FKUI.

[14] Kaat, A. J., Lecavaller, L., & Aman, M. G. (2014). Validity of the Aberrant Behavior Checklist in Children with Autism Spectrum Disorder. Journal of Autism and Developmental Disorders, 44(5), 1103-1116.

[15] Kinnealey, M., Pfeiffer, B., Miller, J., Roan, C., Shoener, R., & Ellner, M. L. (2012). Effect of classroom modification on attention and engagement of students with autism or dyspraxia. American Journal of Occupational Therapy, 66(5), 511-519.

[16] Kranowitz, C. S. (2005). The Out-of-Sync Child: recognizing and coping with sensory integration. New York: The Berkeley Publishing Group.

[17] Lane, A. E., Young, R. L., Baker, A. E., & Angley, M. T. (2010). Sensory Processing Subtypes in Autism: Association with Adaptive Behavior. Journal of Autism Development Disorder, 112-122. DOI 10.1007/s10803-009-0840-2

[18] Lechner, N. (2015). Heating, Cooling, Lighting; Sustainable Design Methods for Architects. New Jersey: John Wiley & Sons, Inc.

[19] Leestma, D. P. (2015). Designing for the spectrum: An educational model for the autistic user. University of Maryland, Faculty of the Graduate School.

[20] Long, E. A. (2010). Classroom Lighting Design for Students with Autism Spectrum Disorder. Kansas State University, Department of Architectural Engineering and Consruction Science College of Engineering.

[21] Mahnke, F. H., & Mahnke, R. H. (1993). Color and Light in Man-made Environments. Canada: John Wiley & Sons.

[22] Mayes, S. D., Cahoun, S. L., Aggarwal, R., Baker, C., Mathapati, S., Molitoris, S., & Mayes, R. D. (2013). Unusual fears in children with autism. Research in Autism Spectrum Disorders, 7(1), 151-158.

[23] McCormick, C., Hepburn, S., Young, G. S., & Rogers, S. J. (2016). Sensory symptoms in children with autism spectrum disorder, other developmental disorders and typical development: A longitudinal study. The SAGE Glossary of the Social and Behavioral Sciences(5), 572-579.

[24] Mostafa, M. (2008). An Architecture for Autism: Concepts of Design Intervention for the autistic user. International Journal of Architectural Research, 2(1), 189-211.

[25] Mostafa, M. (2014). Architecture for autism: Autism aspectss ™ in school design. International Journal of Architectural Research, 8(March 2014), 143-157.

[26] O'Connor, Z. (2011). Colour psychology and colour therapy: Caveat emptor. Color Research and Application, 36(3), 229-234.

[27] Samson, A. C., Hardan, A. Y., Lee, I. A., Phillips, J. M., & Gross, J. J. (2015). Maladaptive Behavior in Autism Spectrum Disorder: The Role of Emotion Experience and Emotion Regulation. Journal of Autism Development Disorder. doi:10.1007/s10803-015-2388-7

[28] Sánchez, P. A., Vázquez, F. S., & Serrano, L. A. (2011). Autism and the Built Environment. In Autism Spectrum Disorders - From Genes to Environment. InTech.

[29] Shabha, G., & Gaines, K. (2013). A comparative analysis of transatlantic design interventions for therapeutically enhanced learning environments - Texas vs West Midlands. Facilities, 31(13), 634-658.

[30] Shattuck, P. T., Seltzer, M. M., Greenberg, J. S., Orsmond, G. I., Bolt, D., Kring, S., . . . Lord, C. (2006). Change in Autism Symptoms and Maladaptive Behaviors in Adolescents and Adults with an Autism Spectrum Disorder. Journal of Autism and Developmental Disorders, 1735-1747. doi:10.1007/s10803-006-0307-7

[31] Szokolay, S. V. (2004). Introduction to Architectural Science : The Basis of Sustainable Design. Oxford: Architectural Press : an imprint of Elsevier.

[32] The Ministry of Women Empowerment and the Child Protection Republic of Indonesia. (2018, April 28). Kementerian Pemberdayaan Perempuan dan Perlindungan Anak RI. Retrieved from Hari Peduli Autisme Sedunia: Kenali Gejalanya, Pahami Keadaannya: https://www.kemenpppa.go.id/index.php/page/read/31/1682/hari-peduli-autisme-sedunia-kenali-gejalanya-pahami-keadaannya

Journal of Accessibility and Design for All

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

ARCHITECTURE CHALLENGES IN ATTAINING INCLUSIVE EDUCATION FOR PEOPLE WITH DISABILITIES – SHARING EXPERIENCE FROM KOSOVO

Arta Basha-Jakupi[1], Gresa Morina[2], and Dukagjin Hasimja[3*]

[123] Faculty of Architecture, University of Prishtina, Prishtina, Kosovo

[1] ORCID: https://orcid.org/0000-0002-6430-4850

[3]dukagjin.hasimja@uni-pr.edu

[*] Corresponding author

Received: 2021-10-09 | Accepted: 2023-03-05 | Published: 2023-05-31

Abstract*: *Background: Education is continuing to develop different academic roles and services to meet the needs of society. The important value of education is more underlined in their built environment when they were supposed to undertake careful designs to avoid non-accessibility among space users. They also aim to create a good, efficient, and safe environment inside their premises. The built environment is a severe share of people with disabilities (PWDs)* attendance and continuation of the educational cycle.

Objectives: Exploring the preparedness of the educational built environment in Kosovo for the PWD's accessibility concerning building design modifications when ensuring adequate education, socialization, and a safe environment. Consequently, it reveals the contrasting ways architects and educational institutions outline and design for PWDs, and the range of doubtful models and approaches they bring to bear upon processes of architectural production and designing for PWDs (Hall et al., 1999). Furthermore, to understand the importance of architecture as one of the main factors influencing the education cycle of PWDs. Finally, and most importantly, how architecture causes this journey to stop.

Methods: The descriptive research method's survey, observation, and case study approach helps investigate the topic more in-depth and multi-sided. The research is conducted in all four educational levels: preschool, elementary school, high school, and higher education institutions.

Conclusions: All four educational levels (preschool, elementary school, high school, university/college) showcase more or less the same physical barriers, but what needs to be noted is that the higher education facilities foster more PWDs accessibility than preschool or elementary school. Nevertheless, it is of utmost importance that the first levels of educational facilities have fulfilled the universal design standards, thus not discontinuing the educational cycle from the beginning and creating involuntary isolation and social non-inclusion. As a result, it will further influence thinking and how architects design in their practice besides sharing Kosovo's experience. The concept deals with the recommendations proposed on two scenarios for the Kosovo relevant institutions, the architect's community and educational institutions.

Keywords: architecture accessibility, design for all, Kosovo, educational facilities

Introduction

Producing architecture for every kind of user will mean improving accessibility for those with disabilities. However, designing for People with Disabilities (PWDs) is often an afterthought of the creative process (Boys,2014). The accessibility of PWDs has been a sensitively debated topic in the Kosovo architecture realm. It happens because PWDs have only sometimes been part of society. Consequently, their needs have been ignored. Numerous campaigns and advocacy for the rights of persons with disabilities in Kosovo have gained momentum in recent years. However, the participation of PWDs in public life continues to present challenges. Among the most underlined remains the built environment, the architectural design that does not treat all people's needs equally. Furthermore, it is the contrasting ways architects and educational institutions define and design for disability and the range of doubtful models and approaches they bring to bear upon processes of architectural production and designing for PWDs (Hall et al., 1999). It needs to be noted that this article targets people with physical disabilities who use wheelchairs; therefore, in most cases, the taxonomy of wheelchair users will be encountered.

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

In Kosovo, statistics do not provide the exact number of people with disabilities, although there are 18,000 PWDs members at the NGO Handikos (HandiKOS, 2019). However, based on World Health Organization principles, according to which 10 to 15 percent of the population in the world live with disabilities, then, it turns out that in Kosovo, about 150 thousand to 255 thousand people belong to this category (Kasapolli-Selani, 2016). Given this large number of PWDs, fundamental human rights need legal recognition. Unfortunately, even though Kosovo provides a legal framework for PWDs, only 30% of the required international standards are integrated into the applicable laws governing these issues. Accessibility is one of the basic categories of disability rights. Therefore, improving the legislation on disability according to international standards by the Kosovo Institutions remains critical. According to the national laws and bylaws for the rights of PDWs, every person with disabilities enjoys the same right to education as any other person. Therefore, through educational institutions and those who manage education, the state must register, accommodate, and provide quality and proper education for everyone (HandiKOS 2019).

But on the other hand, the education of people with disabilities is only 30%. Therefore, it is vital to explore the preparedness of the educational built environment in Kosovo for the PWD's accessibility concerning building design modifications when ensuring adequate education, socialization, and a safe environment. Furthermore, to understand the importance of architecture as one of the main factors influencing the education cycle of PWDs. Finally, and most importantly, how architecture causes this journey to stop.

Access is not merely physical access.

We live in a world where individual movement, autonomy, and personal competence are highly valued and seen as ordinary. While people who are less than fully mobile, dependent on others, or seem "slow" become a problem (Boys 2014). The social environment is not open to the possibility of disability; in other words, the social climate often creates the opportunity for disability (Davis 1995). These physical or mental disabilities acquired from this environment often become connotations for accessibility (Rapley, 2013; Cook et al., 2012). And when it comes to architectural design, accessibility always

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

comes as a peripheral consideration of the project and not as a fundamental thing.

In the design process in architecture, the approach should be considered a starting point, a need, and part of the concept. To better understand accessibility, the questions can be regarded as what is becoming accessible, and how is it becoming accessible? (Boys 2017) In the first question, it is always important to consider the prospective users, the function and destination of the building, and the spaces that PWDs need to utilize. Equipping buildings with architectural elements for the physical access of PWDs is only a tiny part of where architects need to focus (Imrie, 1998; Jackson, 2018). These elements are not enough to ensure accessibility to school activities. They facilitate access but just cannot be defined as access. Planning for comprehensive activities and the proper design of spaces represent a part of accessibility. The other part also penetrates all users' diversity in those spaces (Libertun de Duren et al., 2021).

Physical Disabilities and Education

If we look back at the history of people with disabilities, we see that they have permanently been excluded from the general education system by placing them in special schools. In addition to this categorization, their number in primary education registration is deficient. Therefore, even if they continue their education, most likely, these children will leave school earlier and without going to high school and beyond (Graham et al., 2019).

The lack of accurate statistics on the number of PWDs in Kosovo at the central level is a controversial issue, which also lacks the exact number of children attending school or not. However, the UNICEF Office in Kosovo has estimated that out of 43,000 children with disabilities, only 5,300 participate in regular public schools in Kosovo. Meanwhile, 38,000 children with disabilities in Kosovo do not attend school (UNICEF, 2019). Primarily it starts with social norms, which tend to stigmatize PWDs and remain with physical obstacles such as lack of adequate facilities (inaccessible classrooms and toilets) and unsatisfactory specialist support (UNICEF, 2019).

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

Previously, the accessibility issue in educational institutions has been addressed scarcely on some small-scale projects, with a large part of the responsibility belonging to the architect. As a designer of the most built environment, the architect did not foresee the PWD's accessibility despite laws and administrative instructions regulating planning without barriers (Demjaha et al., 2002). Following this trend and according to the HANDIKOS report about the assessment of the accessibility of primary and lower secondary school buildings for children with disabilities in Kosovo, the following was found: ramps do not exist in 18% of the assessed facilities, while 55% of them are not built according to standards; in 72% of schools, there are no accessible toilets; 89% of schools have no elevator at all; out of 144 schools, access markings were encountered in only a few cases; 21% of schools do not offer enough space in the classrooms; while parking lots are 100% inaccessible (Basha, 2016). The deficiency of access to public spaces and amenities rejects PWD's unrestricted and independent movement, particularly in educational amenities requiring equal social participation. Moreover, the inadequacy of public amenities excludes them from public services while denying them the right to schooling, leading them to involuntary isolation (Basha, 2016).

Understanding why and how people are excluded gives us practical steps toward a comprehensive model. According to Microsoft, while accessibility is an attribute, inclusive design is one method. And while practising inclusive design should make products more accessible, it is not a process to meet all accessibility standards. Ideally, accessibility and inclusive design create experiences that are compliant with standards and truly usable and open to all (Microsoft 2016). Unfortunately, many architecture schools often refer to the inclusive design as something to think about later or as something that is added retroactively to the project. Even when we extend the idea of inclusive design, the problem remains: it is treated as something subsequent that has nothing to do with the architecture itself but brings up a discussion only after the architecture is complete (Imrie et al. 1996).

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

Methodology

This paper's compilation is done descriptively using different data collection methods. Therefore, a considerable part of the paper consists of collecting and reviewing the existing literature in the theoretical and practical context of the national and international levels—the literature consists of books, various recordings, biographies, published statistics, scientific articles, etc. After analyzing these data, several educational institutions of different levels were randomly selected as case studies. In these cases, the study evaluated and identified the physical accessibility for PWDs. These assessments were made in the last two weeks of October 2020.

Furthermore, the blueprints of the plan were taken from the City Archive, and the changes these buildings have undergone to date were identified and investigated further. In addition, the architectural obstacles that people with wheelchairs encounter inside the buildings have been documented with photographs. Together with assessing technical requirements that a project must meet in Administrative Instruction no.33 / 2007 (MMPH 2016).

Further, quantitative research methods with qualitative elements are used, a mixed research model. Primary data collection and analysis consisting of questionnaires and semi-structured interviews were performed. The questionnaires were equipped with closed and open questions. Two questionnaires were developed addressing two community groups, people with physical disabilities - wheelchair users, and the community of architects (a total of 98 questionaries', with eight questions). These questionnaires were received in digital form in January 2021. The data was collected anonymously, except for interviews where respondents could display their names. Finally, after completing the research study, the results of this data were evaluated and quantified. The investigation line culminates with a proposition of two possible scenarios that can address the subject of the study.

Study analysis

Considering the findings in the research conducted by HANDIKOS, it was evident that most schools have problems with physical accessibility. Extending

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

the research in a narrative form on the educational journey of PWDs, several buildings of different levels of education have been selected by following the schooling path from preschool to higher education institutions. Accessible and inaccessible constructed and programmatic components of a facility of Universal Design are included during the analyzed case study considerations (Board 2015). The idea was to understand which levels of education could be clogged or do not provide a friendly user space for PWDs. The case studies were chosen randomly, even though all have a central position in the city and are very much frequented (fig. 1). Their prominent role in the capital of Kosovo sufficiently explains the accessibility and inclusion of PWDs at the state level. It should also be considered that the number of PWDs in some of these institutions goes to none; among other factors is the presence of numerous architectural barriers to wheelchair users. The analysis is done at the Preschool institution “Xixëllonjat”; Elementary School “Hasan Prishtina”; High School “Xhevdet Doda”; and the Faculty of Law and Economics at the University of Prishtina.

Figure 1. Selected case studies in the city of Prishtina (author: G. Morina).

Preschool Institution 'Xixëllonjat' (fig.2) was built in 1945. Its primary function was a health care centre, which was later adapted to its current function. It is positioned in the central area of Prishtina, which makes it easily accessible, although the topography in this part is a bit steep. Unfortunately, this kindergarten does not have PWDs parking. An architectural barrier

perceived at the entrance of the building does not allow children in wheelchairs to even enter the facility, much less to be involved in the educational process. The building is B + G, and all the classrooms are

Figure 2. Preschool Institution-physical barriers (author: G. Morina).

Position on the ground floor makes the classroom's horizontal traffic easily accessible. Since the basement is used only by the staff, this does not interfere with the free movement of PWDs. Toilets are among the spaces where PWDs could find problems using the small available space. In addition, the doctor's and administration office doors present barriers that would be difficult to cross. The materials used on the floor are parquet and tiles, wherein some parts are covered with carpet. The latter may show difficulty in manoeuvring the manual cart less freely and less in the electric one.

On the other hand, in the outdoor areas, it is noticed that the courtyard area does not provide space for play for wheelchair users. In addition, the pathway to the sports field makes access difficult and denies it overall (fig.2). Analyzing the gathered data. Each barrier causes a different difficulty leading to a chain of obstacles, which further causes the exclusion of almost all activities a child in a wheelchair may encounter in this building.

Primary school 'Hasan Prishtina' - was built in 1968, with 2187 students. This school is located in the Ulpiana neighbourhood, Prishtina. This building has a central position, but the topography in this location is quite steep. Access to the facility is challenging if the student in a wheelchair wants to go to school independently, especially when the plot does not have parking. The main entrance to the courtyard consists of several ramps built temporarily to carry goods for the school and by no means for PWDs.

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

Figure 3. Location of the gymnasium "Hasan Prishtina" in the city of Prishtina and identification of the physical barriers (author: G. Morina).

Therefore, these ramps are not equipped with the correct elements and do not possess the proper slope for a wheelchair user. Moreover, it further increases the risk of their use. It needs bypassing with assistance on these ramps. The communication between the outer and inner space is on the same level. Although the doors are wide and easily passable, several other obstacles prevent further movement (fig. 3). The interview with the school's deputy director discussed how the inaccessibility in this school was highlighted during an event they had at their school. When Janis McDavid, motivational speaker and wheelchair user, visited the school, the latter had to improvise a ramp to attend the event, where he was the main protagonist (fig. 3). This highlighted the school's shortcomings further pushed forward the concern about the accessibilities of PWDs. It is more than evident that when this facility was designed, the rights of PWDs were not appropriately respected. The numerous barriers in this building mainly come from the slope of the terrain but without leaving aside the time when it was built. A person in a wheelchair attending this school can use the spaces, with someone's assistance at the main entrance hall, the two classrooms on the -2nd floor, and the football field in the schoolyard. The non-accessibility usually affects most classes they must attend, such as physical education, computer science, and other activities and events in the meeting room or different parts of the school. Most of these kids'

activities are trivial and are just trying to navigate a built environment where they are ignored.

High school "Xhevdet Doda"- is among the newest buildings investigated, built in 2010 and located in the neighbourhood Lakrishtë, a school of 1178 students. The pathway toward the entrance is flat and easily accessible. The plot has parking spaces but no parking dedicated to PWDs. The main entrance to the building consists of a ramp and stairs. Currently, this ramp has a distance of 10 meters and a slope of 9% (fig. 4). According to the Administrative Instructions, this may affect the independent movement of PWDs who need to pause and have time to rest after 6 meters of ramp length.

Figure 4. Location of the gymnasium "Xhevdet Doda" in the city of Prishtina and identification of the physical barriers (author: G. Morina).

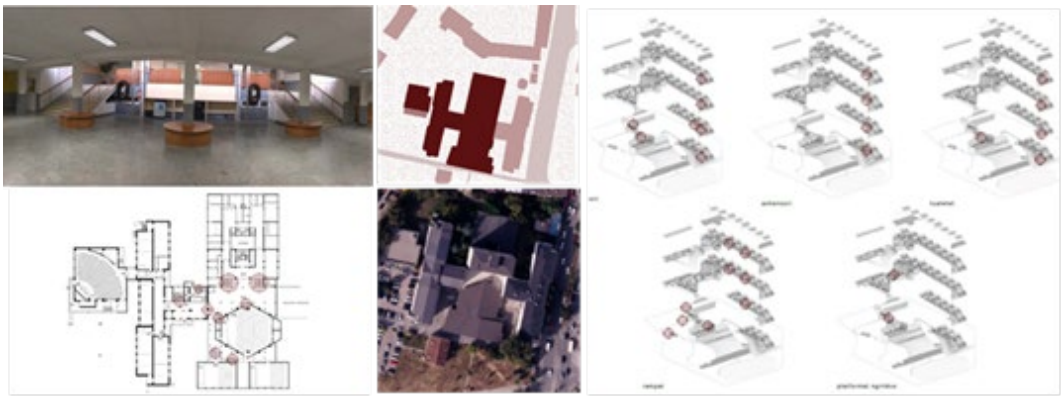
The most accessible space of the building is the generous multifunctional area that allows students to participate in various activities. Although this facility has provided a ramp to the main entrance, it further deprives PWDs of participating in activities in other spaces, such as the outside sports field, the locker room in the gym, the library, the computer cabinet, and other cabinets. In addition, a lack of vertical circulation leads to separation from their peers in leisure activities and other classes. The building has a toilet dedicated to PWDs but lacks all the necessary elements. The abovementioned barriers are

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

encountered on the ground floor, while the upper floors are inaccessible. Interviews with PWDs in higher education and those at high school have shown more discomfort in seeking help. All the more so when the design constantly highlights this need. Although this building offers more opportunities than other study cases, taking into account its recent construction, it still does not meet all the requirements that a student in a wheelchair needs.

Higher Education Institutions - Faculty of Law and Economics, UP "Hasan Prishtina," was established in 1961. This faculty has a central position and is part of the university campus in Prishtina. The path to the building is mainly flat, with a slight slope. The plot has parking lots, but no parking is marked for PWDs. The main entrance to the building consists of a ramp and stairs. Although the ramp has the proper slope, it does not possess the handrails for support. This faculty is filled with unevenness, degrees, and barriers that deny students with wheelchairs to run the administrative services independently, hold all lectures in the respective halls, consult with professors, etc. (fig.5). At this level of education, the level of awareness about physical barriers and the solidarity of others is even higher. With almost minimal investment, the potential for adaptation of these two integrated faculties could be accessible to wheelchair users.

Figure 5. Identification of barriers in the Faculty of Economics and Law (author: G. Morina).



Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

Discussion and proposal

All identified problems on the investigated buildings of four levels of the educational cycle are presented in the table (fig.6). It is evident that all four levels continue the pattern of difficulties that PWDs encounter during their education.

Figure 6.Accessibility table for all four case studies (author: G. Morina).

	Pre school	Elementary school	High school	University
Accessible entrance	x	x	♿	♿
Internal ramps	Not necessary	x	x	x
Elevator	x	x	x	x
Flooring	♿	♿	♿	♿
Accessible doors	♿	♿ only in class	♿	♿ only in some class
Accessible hall	♿	♿	♿	♿
Accessible toilet	x	x	♿	♿ nonfunctional
PWDs parking	x	x	x	x
Inclusion of PWDs in all activities	x	x	x	x
Inclusion of PWDs in all classes	x	x	x	x
Free circulation in wheelchair	♿	♿	♿	♿ only in some class
Inventory	x		x	x
Access to school management, administration	x	♿	♿	x

What PWDs take from their study experience is minimal activities, where all actions depend on others, thus highlighting their disability. By analyzing case studies, questionnaires, and interviews with wheelchair users who are still attending school or even those who have completed their studies, it has been understood that earlier levels of education show more significant motivation for intervention. Thus, by addressing the root of the problem and intervening at this level, PWDs education could take a different direction. Many schools need to provide space and opportunities to include PWDs in the learning process. Accessibility remains one of the most critical factors that directly affect the furtherance of PWD's education. Research has also shown that sometimes more than just one ramp at the main entrance is needed to solve the whole problem, so it is essential to understand how the building functions and how the PWDs should be included.

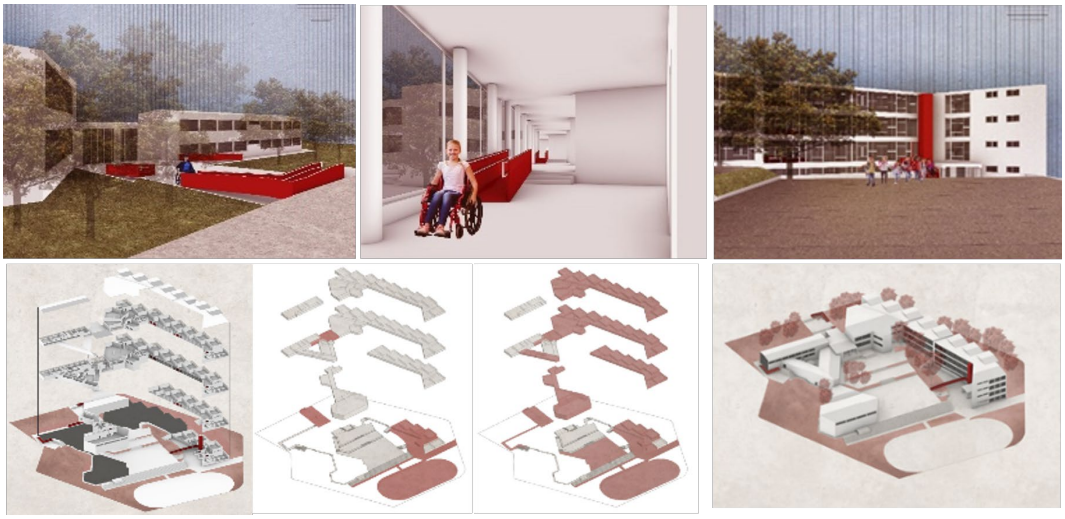
Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

The investigation line of the research progresses the study in two possible scenarios/proposals, targeting the elementary education level. The gathered research shows that the buildings of this level are significant to improve and are the critical levels of the educational cycle. However, different impetus can be triggered for all other levels. The first scenario is the possible minimal interventions (adds on) in the "Hasan Prishtina" school, an actual building. And second is a proposal for a new project (elementary school) in Arberia. Both of the proposed scenarios have different approaches to the planning process. The first one is after the building has been finished and the PWDs accessibility features have been added in the post-course. The second scenario gives a contrasting approach, whereas it starts from the PWDs accessibility and develops further the school design.

In the first scenario, the “Hasan Prishtina” addendum. Primarily, the physical barriers that pose mobility challenges are targeted, followed by discovering the possible interventions. The proposal significantly improves the PWD's free movement in the entire building. Initially, ramps were proposed at the main entrance, along with the stairs, and were moved inside the plot, thus freeing the sidewalk (fig.7). PWDs toilets have also been proposed, with minimal needed dimensions. For vertical communication, the new proposed elevator is also an integral part of the bridge that connects floor -1 with a part of the courtyard that leads directly to the sports hall (fig.7). A ramp at the entrance to the pre-primary level has been proposed. However, it has been impossible to intervene from the main entrance due to the narrow space. Therefore, a lifting platform was added to the main lobby and sports hall area, allowing PWDs access to the game room and other classes. The improvement of PWDs circulation in this building is shown in red (fig.7), representing the spaces with improved circulation. In white, some areas cannot be improved with minimal interventions. Therefore, a compromise to alleviate the situation should be considered and make the building accessible to almost all school activities.

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

Figure 7.The first scenario design intervention at the primary school " Hasan Prishtina" (author: G. Morina).

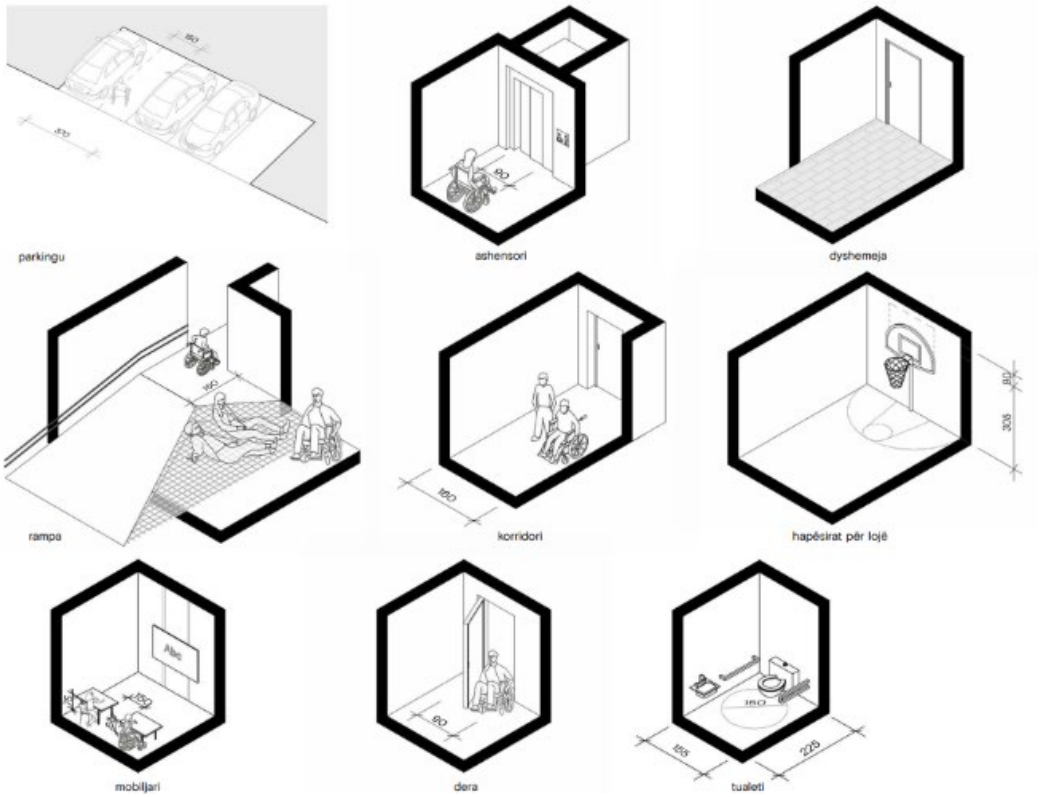


By making this building accessible to all, the school's quality will increase. In addition, all children who use wheelchairs will have the opportunity to enjoy the school experience alongside their peers. Rather a society with a large circle of diversity is a healthy and promising society for the future.

The second scenario is the Arberia project. Recommendations of a prototype starting opposite the first scenario derived from situations where the building's intervention for free PWDs accessibility is impossible. Therefore, it is essential that during the design process of new projects, the needs of PWD are considered so as not to create problems that will later try to be solved. To have the best possible accessibility for PWDs, some architectural elements that have emerged from this research should be considered (fig.8). Also, these elements can be the starting point of the design process, making the whole design process more integrative.

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

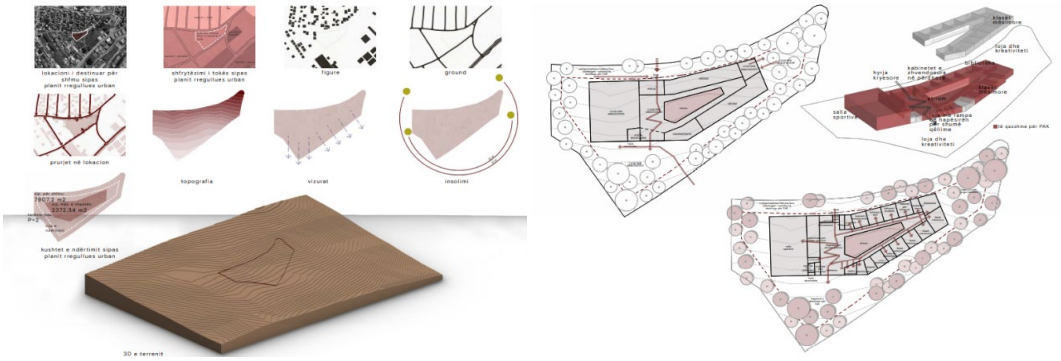
Figure 8. Accessibility premises (author: G. Morina).



According to the urban development plan of Prishtina, a new school is foreseen in the Arbëria neighbourhood. The aim is to develop a new school project with inclusive planning and design. The proposed functional scheme provides a conceptual solution of design that would give a more comprehensive approach. The operational plan has all the cabinets and some classrooms on the ground floor (fig.9). The classes are oriented to the southeast. In contrast, the cabinets have been moved to the north side, with lateral lighting from the proposed atrium. A direct connection has also been made from the main entrance to the southern part where the courtyard is located. This connection, along the way, passes through the multipurpose area, which can be equipped with ramps as a practical and creative solution. At the end of this space is the student's café, which could be part of the ramp composition, while its direct connection with the outdoor area offers a relaxing space for all students. Since on the west side, the slope of the terrain is greater; the sports hall has been located to that part to respect the height in the context of the location.

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

Figure 9. Second scenario proposal, new design project (author: G. Morina).



Although physical resilience does not entirely solve the inclusion of PWDs in society, it is the first and crucial step to achieving it. Therefore, such an advancement leads to a more integrative community. As an outcome of two scenarios and all the above investigation, this paper aims to conclude some general recommendations to the Kosovo relevant institutions and beyond: People with disabilities to become part of the design process in public projects; Simulation of disabilities leads to different stereotypes, so it is recommended that interaction between architects and PWDs be more significant to understand their needs better; The exchange can start from the schools of Architecture where PWDs can be invited and give their perspective. Whereas their needs can be used as a source of inspiration for creative design, rather than replicating solutions, Accessibility codes and rules may be more comprehensive but also more flexible. By giving people with disabilities all the opportunities for their education, we open the doors for those who further want to study architecture. This way, we would have more qualitative input from a person who faces disability and architecture professionally. Given that architecture was born in the past as a constant human need to adapt continually, today, it needs to adapt equally.

Conclusion

This research has come to understand the importance of including PWDs in society. Their right to education is protected by law and conventions, so the state must take appropriate measures to eliminate barriers and inaccessibility. In including PWDs in regular classes, the necessary tools and actors in the learning process should be provided. With the proper implementation of inclusive education, other students can also benefit. The interaction of

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

architects and PWDs should be more notable, whereas their needs can be used as a source of inspiration for creative design rather than replicating them as solutions. All four educational levels (preschool, elementary school, high school, university/college) showcase more or less the same physical barriers. However, higher education facilities foster more PWDs accessibility than preschool or elementary schools. However, it could be more related to the activities accommodated in different educational levels, such as the one combined with play and physical activity, as well as the ratio of the higher education facilities with the overall population. Nevertheless, it is of utmost importance that the first levels of educational facilities have fulfilled the universal design standards, thus not discontinuing the educational cycle from the beginning and creating involuntary isolation and social non-inclusion.

Furthermore, this should be regarded when starting new projects by offering the broadest possible flexibility for future users. In addition, architects need to look beyond standardized solutions and bring innovative solutions through these elements for all groups in society. Considering the needs of others in the original design, rather than adapting one to fit additional requirements, could be what helps identify deficits in the design that the architect may have yet to consider. The best-designed public building projects improve the lives of all users of that building; by thinking creatively and with a great design, beautiful accessibility creates spaces that welcome everyone (Mortice 2019). Using inclusive design and inclusive schools, all children create influential personalities with excellent potential for empathy. Accessibility is more than physical access; it includes PWDs in society. Thus, they are a considerable advantage for society in the long run.

Acknowledgements

The studies reported in this article are extensions of the master thesis done by Gresa Morina, mentored by Arta Basha – Jakupi, and supplementary observations by Dukagjin Hasimja. This research received no specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

References

[1] Basha, R., HANDIKOS. (2016). Raport i hulumtimit mbi barrierat arkitektonike në ndërtesat publike në qytetin e Prishtinës

[2] Board, U.A., 2015. Architectural barriers act (ABA) standards.

[3] Boys, J. (2014). Doing disability differently: An alternative handbook on architecture, dis/ability and designing for everyday life. Routledge.

[4] Boys, J. (Ed.). (2017). Disability, space, architecture: A reader. Taylor & Francis.

[5] Cook, V., Griffin, A., Hayden, S., Hinson, J., & Raven, P. (2012). Supporting students with disability and health issues: lowering the social barriers. Medical education, 46(6), 564-574. DOI: 10.1111/j.1365-2923.2012.04267.x

[6] Davis, L. J. (1995). Enforcing normalcy: Disability, deafness, and the body. Verso.

[7] Demjaha, B. Konkkola, M. (2002) Problem apo sfidë? Heqja e barrierave arkitektonike.

[8] Dictionary, O. E. (1989). Oxford English dictionary. Simpson, Ja & Weiner, Esc.

[9] Graham, B., White, C., Edwards, A., Potter, S., & Street, C. (2019). School exclusion: a literature review on the continued disproportionate exclusion of certain. Department for Education. ISBN: 978-1-78105-956-2.

[10] Hall, P., & Imrie, R. (1999). Architectural practices and disabling design in the built environment. Environment and Planning B: Planning and Design, 26(3), 409-425. DOI: 10.1068/b260409

[11] HandiKOS. (2020) International Day of Persons with Disabilities.

[12] HandiKOS. (2020). Historiku, accessed on November 2020, http://handi-kos.org/historiku/

[13] Hanes, R., Brown, I., & Hansen, N. E. (Eds.). (2017). The Routledge History of disability. Routledge.

[14] Imrie, R. (1998). Access in the Built Environment. The disability reader: Social science perspectives, 129-147.

[15] Imrie, R. F., & Imrie, R. I. R. (1996). Disability and the city: International perspectives. Sage.

[16] Jackson, M. A. (2018). Models of disability and human rights: informing the improvement of built environment accessibility for people with disability at neighborhood scale?. Laws, 7(1), 10. DOI: 10.3390/laws7010010

[17] Kasapolli-Selani, A. (2016). Kosova bën pak për fëmijët me aftësi të kufizuara, accessed on November 2020 https://www.evropaelire.org/a/27706536.html

[18] Libertun de Duren, N., Salazar, J. P., Duryea, S., Mastellaro, C., Freeman, L., Pedraza, L., ... & Poitier, F. (2021). Cities as Spaces for Opportunities for All: Building Public Spaces for People with Disabilities, Children and Elders (No. IDB-MG-859). DOI: 10.18235/0003064

[19] MacKay, D. (2006). The United Nations Convention on the rights of persons with disabilities. Syracuse J. Int'l L. & Com., 34, 323.

[20] Microsoft. (2016) Inclusive Microsoft Design

[21] MMPH, Ec Ma Ndryshe (2016) Udhëzim administrativ për kushtet teknike të objekteve ndërtimore për qasjen e PAK

[22] Mortice, Z. (2019). Design for all requires a culture change in architecture. AIA.

[23] Pinilla-Roncancio, M. (2015). Disability and poverty: two related conditions. A review of the literature. Revista de la Facultad de Medicina, 63, 113-123. DOI: 10.15446/revfacmed.v63n3sup.50132

[24] Rapley, C. E. (2013). Accessibility and Development: environmental accessibility and its implications for inclusive, sustainable and equitable development for all. The Department of Economic and Social Affairs (DESA) of the United Nations.

[25] UNICEF. (2019) Kosovo program. Accessed on November 2020 https://www.unicef.org/kosovoprogramme/press-releases/estimated-38000-children-disabilities-kosovo-are-not-attending-school

[26] Wagner, C. V., Soler, S. G., Eddy, M. B., & Liebergesell, N. P. (2017). Four wheelchair-user architects. Universitat Politècnica de Catalunya, Iniciativa Digital Politècnica.

Journal of Accessibility and Design for All

Volume 13, Issue 1. (CC) JACCES, 2023

JACCES

ISSN: 2013-7087

www.jacces.org

Twitter: @Journal_JACCES

LinkedIn: JACCES page

JACCES is committed to providing accessible publication to all, regardless of technology or ability. Present document grants strong accessibility since it applies to WCAG 2.0 and PDF/UA recommendations. Evaluation tool used has been Adobe Acrobat® Accessibility Checker. If you encounter problems accessing content of this document, you can contact us at jacces@catac.upc.edu.