



THE PLACE AND ROLE OF THE CIVIL SECTOR IN THE INCLUSIVE EDUCATION AND DEVELOPMENT OF CHILDREN WITH WILLIAMS SYNDROME (ALSO) THROUGH MUSIC*


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Introduction

■ Williams syndrome (WS) is an extremely rare genetic disorder. Approximately 1 in every 20 000 people has WS. Because of this, most people have never even met a child with WS. Accordingly, it is common and understandable that they know little, if anything, about their condition and the difficulties associated with it. WS is a rare genetic disorder, which is caused by the absence of a particular section of chromosome 7. WS cannot be healed, but with timely treatment and development, symptoms can be alleviated. WS occupies a unique place among genetic disorders because of the fact that, in addition to a unique mix of difficulties, symptoms and abnormalities, some of their abilities and performance in certain intellectual areas are adequate or average, and in many cases above average. Relatively high level of ability includes good communication skills, outstanding verbal skills, sociability and good musical abilities with highly sensitive hearing, good musical pitch and musicality, and a very positive attitude towards music.

As is typically the case for rare disorders, the most important pillar of their advocacy is the civil sphere, where NGOs and foundations support the life, well-being, development and education of WS children and families, thus supporting their full life, effective integration into society, inclusion. The great affinity and positive relationship with music justifies that a prominent part of development and inclusion are specifically music-based activities, music-related activities, music therapy activities.

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The above has inspired the research interest and activity to explore NGOs focusing on WS from the perspective of music activities. Accordingly, the main objective of our research is to map NGOs in Europe and beyond whose activities focus on WS patients and their families. The basis for mapping the organizations is to summarize their aims, activities and achievements and to highlight their music-related activities in line with the mission of inclusion. Within this, the presence of music therapy and music education activities, their specificities, implementation possibilities, results and experiences are researched. Our main objective is to show that the development and rehabilitation of WS patients through music and musical activities is a significant and integral part of their care within the organized framework and possibilities of the civil sector.

A basic overview of Williams Syndrome, or what's behind the star eyes and the elfin face

WS (also known as Williams-Beuren syndrome) is a rare genetic disorder (estimated to occur in an average of one in 20,000 births) that causes a wide range of organ disorders through physical and mental developmental disorders and was first described in 1961 as a distinct but related syndrome. It is essentially a disorder of elastin production, which causes a variety of physical and mental characteristics. It can affect men and women equally and has been identified in almost every country in the world. In most families, the affected child is the only affected person (including extended family members) (Bzdúch–Červeňová–Justová 1994). The disease may be caused by the fact that most WS sufferers are missing some genetic material from one of the 7 pairs of chromosomes, including the gene that codes for a protein called elastin. The lack of elastin may be behind the development of the symptoms that characterize the syndrome (Bzdúch–Jariabková 2009).

The main symptoms of WS are: a characteristic „elfin „ face with a short stature, wide eyes with a lacy pattern on either side of the broader, sunken nostrils, swelling around the eyes, protruding wider lips, more distant teeth, small chin; cardiovascular problems; hypercalcaemia¹; low birth weight and/or slow weight gain; feeding problems, abdominal tenderness; dental disorders; kidney disorders; hernias; middle ear infections; hyperacusis²; musculoskeletal problems; overly friendly personality; delayed development; learning difficulties, attention and concentration deficits (Bzdúch–Jariabková 2002). Unfortunately, many individuals with this disorder go undiagnosed or are diagnosed at a relatively late age³. One reason for this is that not everyone has all the symptoms at the same time, so it is not easy to recognize WS. This is a huge problem because, as shown above, patients often face serious and progressive health problems. So early detection is essential for the quality and prospects of life (Pober–Dyckens 1994).



The relationship between Williams syndrome and music, musical abilities

Despite the many symptoms and difficulties, WS is a very special genetic disorder, because despite their developmental deficits, some of their abilities and capacities in some intellectual areas are adequate and sometimes even above average, normal level, and can even reach exceptional levels. These include relatively good language and expressive skills, speaking and communication skills, language comprehension (even in foreign languages), long-term memory, social skills (sociability) and musical abilities and skills (Reis et al. 2000). Children tend to be open, friendly and affectionate. By the time they reach school age, most of them are coherent, fluent speakers. They like to spend time with adults, they like to talk to adults. They are helpful and try to meet expectations. Many of them chat constantly. Their chatting is often superficial, often formal in a way typical of adults, often using clichés and phrases. They find it equally difficult to change the subject of the conversation or, on the contrary, to focus on a particular topic (Jariabková 2001).

Their expressive and verbal skills are often not at the same level. Because of their good speaking skills and friendly nature, they can easily give others the impression that they are capable of more than their real abilities allow. About 90% of WS children are hypersensitive to certain sounds that would not make most people uncomfortable⁴. This phenomenon is called „hyperacusis“. A positive approach to the symptom is the musicality and above average musical hearing (often combined with absolute pitch) that is characteristic of WS. Directly related to hyperacusis is the fact that children with WS are highly sensitive to musical impulses, have a very close relationship with music and show a great interest in it (Campbell 2002). This interest is often associated with above-average musical ability, a good musical sense, a sense of rhythm, sometimes absolute pitch and an excellent musical memory. The literature presents a number of case studies of WS children and adults with exceptional musical performance, not infrequently (at least significantly more often than in the general population) the presence of absolute pitch or other exceptional performance focused on musical domains. In some cases, the name of the syndrome itself is associated with outstanding musical ability, also called singing syndrome, musical syndrome, singing mystery or musicophilia (Sacks 2008).

Specific features of the educational process of WS

It is necessary to involve a whole team of professionals in the treatment of WS, including psychologists, speech and language therapists, physiotherapists, as well as specialists who are familiar with WS. Continuous monitoring is essential for all physical symptoms. The vast majority of WS adults are able to be self-sufficient and attend some form of theoretical and/or vocational training school.



They demand special education, as their needs are quite different from other children's needs, and it can be quite difficult to find an educational institution that fits their specific needs.

Although their verbal skills may suggest a higher level of ability, they may not perform well in a 'normal' school or a strong special school due to their reduced non-verbal skills and concentration difficulties. There is no type of educational institution that perfectly meets the needs of WS.

For WS children, integration can be a workable solution, taking into account the specific characteristics of each child. Of course, only if the institution can provide the appropriate material, physical, personal and mental conditions, the most important of which are: additional adults in the classroom, small class sizes, employment of specially trained teachers and learning assistants, well thought-out and progressive development and work plans, and continuous cooperation between professionals.

As highlighted above, the education and development of WS children requires the cooperation of a complex team, within which support and assistance, beyond specialist medical support, can be approached mainly from the next directions:

- a) Local early development centers, usually with a multi-disciplinary team of experts,
- b) Family support and social care centers, where social problems are solved, counselling, case management and assistance are provided,
- c) Expert Committees for the Assessment of Learning Ability and Educational Counsellors, Pedagogical-Psychological Counselling Centers, the preparation of specialized opinions, individual developmental-educational-educational plans, the elaboration of integrated education conditions,
- d) Various, e.g. foundation-based movement development and rehabilitation centers, play houses – due to the extreme rarity of the disease, it is highly observed that the main pillar of advocacy is the NGO sector, with foundations and organizations helping WS children and their families.
- e) Benefits, rights and equal rights – information regarding benefits for children and their parents is provided by the NGO sector and by local governments and advocacy organizations (Scheiber 2005).

The needs and opportunities for specific educational features should also be considered in the context of music-related activities, considering the special relationship between WS and music and musical skills. Music therapy and music activities of all kinds are an important pillar of integration and inclusion for people with WS, as their highly positive relationship with music, their exceptional hearing and their relatively high level of musical ability provide an excellent basis for development. It is therefore no coincidence that music therapy is a common feature of the work of NGOs. The use of music therapy for children and adults with illnesses, weaknesses and disabilities is a relatively well-documented, well-researched and professionally proven approach. However, the situation is different with regard to education (especially music education at institutional level), since, despite their special



abilities, developmental disorders do not allow WS children to participate in music education within the classical framework of education. In their case, as in education in general, a special approach is needed, adapted to their specific syndrome. However, the possibilities are much more limited.

However, one of the methods of teaching music that stands out as being perfectly adapted to the specific needs of people with disabilities, including WS students, is the *Ulwila color-score method*, created and used by Heinrich Ullrich. It is based on teaching musical elements at a basic cognitive level, using simple symbols, colors and shapes to represent sounds (Tóth-Bakos 2022). Accordingly, sheet music constructed from colored shapes allows the development of musical reading and writing skills, and unique instruments inspired by the method allow active playing of the sheet music - the key to the instruments, in addition to being easy to play, is that they are marked with the corresponding colors for pitch, making it easier to navigate the instrument (Tóth-Bakos 2014, Tóth-Bakos–Csehiová 2016, Tóth-Bakos 2021). The method provides an opportunity for ensembles and orchestras to play together through the sheet music and parts, in addition to individual music making. For WS children and adults, this is an outstanding opportunity to develop their musical skills according to their level, and as well as the experiential and therapeutic effect, educational goals can be achieved, such as developing basic music literacy skills, learning to play an instrument, and playing music in a community.

NGOs in the service of WS in Europe and the world

It is also clear from the above that families with WS children are in an extremely challenging and often difficult situation. It can be observed that they rely most on the support of the civil sector, which is present in countries around the world, and that foundations and organizations focusing on WS and/or other rare genetic disorders are best placed to provide support functions. Why? Firstly, because although these disabled people have a multiple disability, they are not ‚disabled enough‘ for existing civil society organizations to fully represent their specific needs. Since they have only a „few“ of each problem, their symptom complex and their symptomatology are extremely diverse, and their representation and support must be adapted to their uniqueness. Through associations and foundations, people with similar problems can get to know each other. Parents, doctors and teachers can find the right information and exchange experiences. In this way, they can promote their interests together. Since the syndrome became relatively well known, NGOs have been formed around the world to support families with children living with WS and to raise awareness of WS among the public.

These associations were founded by parents who have children with WS, as well as doctors and professionals, to give parents the opportunity to meet, collect information and share their experiences. The organizations are non-profit organizations, usually chaired by a concerned parent or treating doctor.



They receive financial support from membership fees, national and international projects and sponsorship donations.

These organizations have grown into larger entities, federations, and there is now an interconnected network of organizations in Europe and beyond. In Europe, there are currently 19 such organizations, 18 of which are associated with the Federation of European Williams Syndrome (FEWS), the official association of national organizations across Europe which are actively involved in supporting people with the rare genetic condition, Williams Syndrome (WS). The constitution was officially published on September 15th, 2004, in the 'Moniteur Belge' resulting that FEWS has become an official International Organization.

Survey of NGOs focusing on Williams syndrome

Research Aim: Based on the above, we aimed to map and identify the NGOs worldwide that are focused on Williams syndrome, to summarize their main objectives and activities, with a special focus on music-related activities.

Subject of the research: The subject of the research is therefore those NGOs that (also) work with children and adults with Williams syndrome, and their activities include development and musical activities.

Methods used in the research: For the purpose of data collection, the research used mostly explorative methods, with the main background besides printed literature being provided by the web, the organizations' own websites, and materials published or co-published by the organizations themselves. In addition to obtaining available information, the other main pillar of the research methods was based on personal experiences, such as personal experiences collected through personal participation, observation, oral (unstructured) interviews. Personal participation in events organized by the organizations provided an opportunity to collect own active experiences in addition to observations in each activity. Within these frameworks, personal experiences were collected as a participant in the activity or by assisting participants in the activity. In addition, each face-to-face meeting and participation provided opportunities for formal and informal discussions that further enriched the research results. In order to conclude the findings, it was necessary to summarize, analyze and compare the data along several aspects, summarizing and illustrating the results beyond the descriptions.

The research goes far beyond the limits of data collection in that it explicitly required close and active collaboration with organizations, most remarkable being the Hungarian (Magyar Williams Szindróma Társaság), Slovak (Spoločnosť Williamsovho syndrómu) and Czech (Willík – spolek pro Williamsův syndrom). In doing so, they gave us insight into their activities and allowed us to participate actively in events and camps in a helping role, and in addition to answering our questions, they enriched the research results with exceptional results, information and experience by sharing their own stories and actively involving us in the activities



of the organizations. When collecting the research data, it is important to note that the compilation of the list of organizations, i.e. the research sample, was also part of the research work. While the list of members of the aforementioned FEWS is available on their website, the list of organizations worldwide has not been published in the literature available, and therefore the search for organizations individually, their contact details and published information required a significant investment of time and energy.

Research results

In Europe today, there are 20 WS societies in 19 countries – Belgium (two in Belgium), Bulgaria, Czech Republic, Denmark, France, Germany, Hungary, Ireland, Italy, the Netherlands, Norway, Romania, Slovakia, Spain, Sweden, Serbia, the Netherlands, Slovakia, Germany, Switzerland, the United Kingdom and Spain.

Apart from Europe, there are 9 other organizations in Argentina, Australia, Canada, Japan, New Zealand, South Africa, the United States of America and the United States of America.

The objectives and activities of the organizations are varied and depend to a large extent on the financial and social situation in the country. However, we can list some main objectives that are common to all organizations:⁵

- *Finding and linking families with children with WS,*
- *Providing the necessary medical care for children with WS,*
- *Promote the integration of children and adults with WS into society, advocate for their rights and special needs, and support their education and employment in view of their disorder,*
- *Providing opportunities for families of children with WS to support each other and exchange information,*
- *Raising awareness and helping families to solve problems specific to WS,*
- *Raising professional and lay public awareness of WS,*
- *To spread awareness of the syndrome through the press, information, publication of expert articles and studies,*
- *Supporting targeted scientific research projects,*
- *Publication of research results in scientific publications,*
- *Promoting communication with foreign societies.*

These objectives are completed by each organization according to its own skills, capabilities and ambitions. The objectives are achieved through the various activities and events organized by the organizations. There are much greater individual differences between organizations in terms of activities. These differences result from the experience, traditions, financial and other resources of each organization. However, some activities are common to all WS societies:



- *Creation and maintaining their own website,*
- *Organizing professional seminars and training courses,*
- *Support and organization of meetings and meetings of families and children with WS,*
- *Supporting the education of children and adults with WS,*
- *Supporting communication and cooperation with other non-profit organizations,*
- *Production of promotional and information materials and educational films.*

It is also important to mention the other activities promoted by the organizations, which are of great help and support to children and families with WS:

- *Cooperation with hospitals and professional counselling centers, providing consultations and expert advice,*
- *Support for the purchase of compensatory aids,*
- *Organizing summer camps for children and adults with WS,*
- *Support for therapies, in particular music therapy, to improve the health and psychological well-being of children with WS and their families,*
- *Self-publishing, translation of foreign literature, acquisition of foreign professional materials,*
- *Publishing own journal.*

In the field of research and publication, we can highlight the German organization, which is the only one in Europe to publish research on the musical abilities of children with WS. Several organizations in countries such as Germany, Belgium, France, Hungary, Ireland and Spain have contributed significantly to the publication of their own books dedicated to the syndrome. Organizations in Ireland, England, Italy, the Netherlands, Sweden, the Czech Republic, Hungary and the United States are particularly active in producing promotional films and other information materials about WS. Some organizations publish their activities in their own magazines, e.g. in Slovakia, the Czech Republic, Denmark, the Netherlands, Spain, Sweden and Denmark.

Each of these organizations organizes camp-like activities for children, adults and their families with WS. However, not all associations are able to manage these events on their own. Some societies organize summer and weekend activities in partnership with other non-profit organizations, such as rare genetic disease societies and organizations for people with physical and mental disabilities.

It is important to point out that not all WS societies are made up of WS people and their family members. In countries where there are no specific organizations for people with disabilities, WS societies also include members with other genetic diseases and types of disabilities (such as the Hungarian and Dutch organizations).

Out of the 29 civil society associations (20 European and 9 non-European), we were able to include 19 in our research, of which 18 were European and one non-European. This is due to the fact that some types of organizations, such as federations and foundations, have very different roles in terms of their aims and activities



from the organizational activities we researched, and also because, unfortunately, for some organizations we did not have relevant sources and valid information. Therefore, in order to ensure the validity of the research results, we have only researched the available NGOs, whose full list, country name and website contact details are summarized in the table below (*Table 1*):

Table 1. List of the sample organizations

	Country	Exact name of the organization	Contact details, website of the organization
1.	United States of America	Williams Syndrome Association	http://www.williams-syndrome.org/
2.	England	Williams Syndrome Foundation, LTD	http://www.williams-syndrome.org.uk/
3.	Belgium	Association Belge du Syndrome de Williams	https://www.syndromedewilliams.be/
4.	Belgium	Williams-Beuren Syndroom	https://www.williamsbeuren.be/nl
5.	Czech Republic	Willík - spolek pro Williamsův syndrom	https://www.spolek-willik.cz/
6.	Denmark	Dansk forening for Williams syndrom	http://williamssyndrom.dk/
7.	France	Association Du Syndrome De Williams & Beuren	https://www.autourdeswilliams.org/
8.	Netherlands	Nederlandse Vereniging Williams Beuren Syndroom	https://www.williams-syndroom.nl/home
9.	Ireland	Williams Syndrome Association of Ireland (WSAI)	https://www.williamssyndrome.ie/
10.	Hungary	Magyar Williams Szindróma Társaság	https://www.williams.org.hu/
11.	Germany	Bundesverbandes Williams-Beuren-Syndrom e.V.	http://www.w-b-s.de/
12.	Norway	Norsk Forening for WS	https://www.nfws.no/
13.	Romania	Asociația Williams Syndrome România	https://www.williams-syndrome.ro/
14.	Italy	Associazione Italiana Sindromo di Williams (AISW)	https://www.aisw.it/
15.	Russia	Russia Благотворительный фонд поддержки людей с синдромом Вильямса	https://williams-syndrome.ru/
16.	Spain	Asociación Síndrome Williams España	http://www.sindromewilliams.org/



17.	Switzerland	Vereinigung Williams-Beuren Syndrom Schweiz	https://www.williams-syndrome.ch/
18.	Sweden	Williams syndromförening i Sverige	http://williamssyndrom.se/
19.	Slovakia	Spoločnosť Williamsovho syndrómu	http://www.spolws.sk/

The following we summarize and we present the main activities of the 19 organizations surveyed, the characteristics of the events they organize, the presence and nature of music-related activities and information on music education and music therapy.

The organizations can be assessed in terms of their activities according to three main criteria:

- activities targeted only at children and adults with WS,
- common activities for members with WS and their families,
- activities for parents and accompanying participants only, and activities for those interested in the topic.

Summarized according to the criteria listed, the following activities were found in the organizations surveyed (*Table 2*):

Table 2. Classification of activities managed by organizations

For children only	For parents and accompanying only	Common
Rehabilitation treatments	Consultation with experts	Summer and/or weekend camps
Summer and/or weekend camps	Conferences, seminars and workshops, expert lectures	Various leisure activities during the camps (excursions, sports, arts and crafts, etc.)

Each NGO organizes or co-organizes its summer and mid-year or weekend camps, which in some cases are for WS children and adults only, and in other cases also for their families. In both cases, they have in common the participation of volunteers who assist in the daily care of children and adults with WS as guides. Within this framework, only they are present as helpers in the activities organized for the children, during which the parents can participate in other events kept for them. They are also available throughout the camps to assist families with daily tasks, evening activities and recreational activities, thus ensuring the smooth running of the camps. Volunteer helpers are most often university students whose studies are directly or indirectly linked to the work of the assistants – special education students, teacher training students, social education students, but there are also some who are motivated to volunteer by their passion for volunteering.

Camps are most often held during the summer months, but shorter mid-year camps are held throughout the year, focusing on the weekends. The activities of



summer, weekend or mid-year camps can be divided into daytime and evening programs. The daytime activities include professional programs for WS participants and parents, as well as other leisure activities. The main aim of the evening activities is to provide entertainment, fun, socializing and more informal activities. Most of the daily programs are developmental, therapeutic and rehabilitative programs and led sessions for participants, delivered by qualified activity leaders with the assistance of helpers, based on a pre-planned and scheduled program. These therapeutic activities include music, music-based activities, mainly in the form of music therapy sessions or music activities led by other professionals. Some NGOs carry out such musical activities only during the summer or other camp-type events, while others hold them on a weekly basis throughout the year.

Musical activities organized by the NGOs surveyed. Out of the 19 organizations surveyed, 12 have music-related activities, such as Hungary, Slovakia, Czech Republic, Ireland, England, Sweden, Spain, the Netherlands, Italy, Norway, Belgium (Flemish organization), United States of America. For the remaining 7 organizations, no information on music-related activities was found.

Musical activities include:

- music therapy,
- music camps,
- participation in an ensemble or band,
- attending musical events,
- music education.

The presence of music-related activities among the organizations providing music-related activities is very diverse, and the following table indicates the music-related activities that are specific to the countries and that are carried out along the lines of the previous list (*Table 3*):

Table 3. Musical activities organized by NGOs

Country	Music activities				
	Music therapy	Music camp	Playing in a band	Visiting events	Music education
Hungary	✓	✓	✓		✓
Slovakia	✓				
Czech Republic	✓				
Ireland		✓	✓		✓
England			✓		
Sweden		✓	✓		✓
Spain	✓				✓



Netherlands			✓		
Italy	✓				
Norway	✓	✓			
Belgium				✓	
United States of America		✓			✓

Analysis of the data presented shows that six of the organizations focus specifically on one type of music activity. Slovakia, the Czech Republic and Italy provide only music therapy sessions, England and the Netherlands offer the possibility to participate in a band, Belgium focuses on attending music-related events. The activities of the organizations in the other countries are linked to music and music-related activities in a variety of forms. Among the types of activities, three countries offer two different types of music-related activities. While Spain focuses on music therapy and music education and Norway on music camps in addition to music therapy, the US organization focuses on music camps and music education. The remaining three countries are especially active in the delivery of music-related activities, Ireland and Sweden offer three types of activities, in the form of music camps, playing in a band and music education, and Hungary offers the most, with four types of activities, in addition to music therapy.

Another finding is that of the organizations that participated in the research and organized music-related activities, six provide music therapy sessions and five also provide music education for children and adults with WS. Among these countries, two, Hungary and Spain, are involved in both activities, i.e. the organization of therapeutic and educational music activities. Of the NGOs organizing music therapy sessions, all 5 countries' NGOs organize group music therapy sessions, while NGOs in Hungary, Slovakia, the Czech Republic and Norway also organize individual therapy sessions for their participants. All five countries also offer active and receptive as well as complex music therapy sessions. In practice, this means that sessions include all elements of music, a wide range of musical activities, active music-making and combining music with other activities, in addition to listening to music, and often instrument-making.

Music camps are camp-like programs where the focus of the activities is almost only on music – introducing music and instruments, gathering and developing musical experiences, active music making and listening to music are highlighted. In total, NGOs from five countries – Hungary, Ireland, Sweden, Norway and the United States of America – organize camps of this kind on a variable basis. Among them, Ireland and Sweden organize also camps with international participation, thus providing opportunities for more countries to participate. Hungary, Sweden and the United States of America also work closely with other institutions to organize this type of event, as described in more detail below.



Within the framework of musical activities, the possibility of *playing in orchestras and ensembles* is a special feature, which, according to the data collected in the research, is also made possible by NGOs in 5 countries: Hungary, Ireland, England, Sweden and the Netherlands. The *Parafónia* orchestra, which has been established in Hungary since 2003, is made up entirely of children and adults with disabilities. The main pillar of their work is based on the Ulwila method, playing on Ulwila instruments using colored sheet music, and the presence and guidance of the band by conductor and volunteers who assist the musicians. The orchestra performs regularly throughout the year, taking part in festivals, and has been recorded for radio and television on several occasions. The Irish organization is one of the largest in Europe and, in addition to local participants, they also provide international summer camps for WS members from other countries. Their main activity during the camps is music education, with individual and group sessions based on the Ulwila colorful sheet music method. In these camps, music ensembles are formed from the members of the camps, which provide an opportunity to play music in community by participating in music groups and ensembles. In cooperation with the UK organization operates the choir named *MiXiT*, which includes young people with various disabilities as well as healthy members. *The Garden of Love op Pinkop*, a band that exists alongside the Dutch organization, is also made up completely of people with rare genetic diseases. The Swedish organization also places a strong emphasis on music and the activities, and their educational opportunities are run in partnership with *Furuboda High School*, where the principles of the Ulwila color-score method are applied. Ensembles are formed within the framework of education; orchestras provide a great opportunity for music-making together. The Irish and Swedish organizations regularly host international summer camps.

The possibility of *attending music-related events* is only specifically mentioned for the organization in Belgium, which does not organize its own music-related activities, but considers it a priority to provide such inspiration and experiences, given the special relationship between WS and music. In addition, other musical activities, such as music therapy, music education, music camps and music-making activities, also include receptive activities aimed at listening to music and receiving musical impulses.

From the point of view of *music education*, the results show that five organizations also provide educational activities: Hungary, Ireland, Sweden, Spain, and the United States. Within this, institutional teaching is available in Hungary, Sweden, and the United States of America.

In Hungary, the Bárczi Gusztáv Elementary School (Bárczi Gusztáv Gyakorló Általános Iskola) in Budapest provides opportunities for music therapy and music education activities not only for WS participants. The institution also functions as a practicing institution of the Eötvös Lóránd University Bárczi Gusztáv Faculty of Special Education (ELTE Bárczi Gusztáv Gyógypedagógiai Kar), which provides an opportunity for close professional and pedagogical cooperation.



The institution works closely with the Hungarian Williams Syndrome Society, especially during the summer camps. In addition to music therapy, the activities also include teaching and learning about the Ulwila method, which is also an opportunity for cooperation with the aforementioned Parafónia music ensemble. The school has a music therapy workshop which, in addition to the therapeutic sessions, also focuses on educational activities based on the principles of the Ulwila method mentioned above.

The *Furuboda High School*⁶ in Sweden provides vocational training for people with disabilities and helps them to find a job after successfully completing their training. The school offers a music course, which includes both theoretical and practical training. The school has its own music workshop and music studio, which provides the possibility to learn to play an instrument, to participate in individual and group music sessions and to participate in orchestras. The institution also organizes short, camp-like international courses as part of its own activities, which focus specifically on musical activities. In the United States, the Berkshire Hills Music Academy⁷ is an institution for the development of musical skills for people with disabilities in the context of institutional education. Its training system is divided into two main parts, the first of which focuses on the development of general and intellectual skills, while the second deals specifically with music. Different types of training are offered, including two-year continuous training, short-term summer camps and summer camps, and training specifically for music therapy.

Summary

The focus of our research was a truly unique approach: we examined the activities of NGOs providing advocacy for WS syndrome, including their musical activities, as a means of inclusion, inclusion, skill and personality development, and social integration.

The specific symptom complex of WS and its special relationship with music and their average or above average musical abilities, the music-related descriptions of the disorder that can be found in the literature, the presentation of cases of WS with exceptional musical talent available in the literature and other documents, all suggest that research on the connection between the disorder and music is timely and important. And research on music-related activities organized and implemented by NGOs is a particularly innovative, gapfilling approach, which is not covered at all or only to a very minimal extent in the available literature. Despite the fact that the disorder itself, the specific symptom cluster of WS, the diagnostic, treatment and developmental options, and the results of the WS are richly represented in the literature, the research results on music are mostly focused on the presentation of outstanding cases and the measurement of musical abilities. There is currently no literature available to explore how and in what ways the WS interest groups, especially the civil sector, integrate music, development through music,



and catch-up into the special care and treatment of WS children and adults. The above-mentioned has inspired us to search for, list and map NGOs worldwide and to collect and summarize all activities related to music.

Our research has shown that NGOs have also recognized the importance of music in WS and that music-related activities are an integral part of their activities. Out of the 19 organizations we studied, 12 were found to have organized their own music-related activities. In the field of music-related activities, five main categories of activities were identified as being present in the activities of the organizations: music therapy, music education, music-related camps, participation in a band and attendance at music-related events. It is worth highlighting the fact that 9 of the 12 organizations that we have studied that organize musical activities have music therapy or music education activities, the main aim of which is to develop, heal and promote inclusion through music. The research also presented the activities of 3 institutions that provide music education and training in an institutional setting, adapted to the specific needs of WS. Our research also revealed that there is a unique method of music education for people with WS, the Ulwila method, which is perfectly adapted to the specific symptom complex of WS and allows for a higher level of music skills and instrumental learning.

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Notes

¹ raised blood calcium level.

² oversensitive hearing

³ Even in the US, only about 25% of patients are diagnosed.

⁴ These sounds can include sudden, loud noises such as thunder, falling objects or the sound of a balloon popping, clapping, electronic noises such as vacuum cleaners, drills and electric razors, loud music and, in some cases, the sound of certain people or laughing.

⁵ The data presented here is based on a summary of the data collected from each organisation, and the information is taken from their websites, the contact details of which are also presented in *Table 1*.

⁶ The source of information is the institution's own website: <http://www.furuboda.se>

⁷ The source of information is the institution's own website: <https://www.berkshirehills.org/>