



CONSENSUS PAPER

for an EU that cares about **Achondroplasia and other** **Skeletal Dysplasias with** **Dwarfism**

Ахондроплазия и други скелетни дисплазии с нанизъм
Achondroplazija i druge skeletne displazije s patuljastošću
Achondroplasie a další kosterní dysplazie s nanismem
Achondroplasi og andre skelettdysplasi med dværgisme
Achondroplasie en andere skelettdysplasieën met dwerggroei
Achondroplasia and other skeletal dysplasias with dwarfism
Achondroplasia ja muud kääbuspuudega skeleti düsplaasiad
Akondroplasia ja muut luuston dysplasiat jotka aiheuttavat lyhytkasvuisuutta
Achondroplasie et autres dysplasies squelettiques avec nanisme
Achondroplasie und andere Skelettdysplasien mit Zwergwuchs
Αχονδροπλασία και άλλες σκελετικές δυσπλασίες με νανισμό
Achondroplasia és más csontváz diszpláziák törpékkel
Achondroplasia agus Dysplasias Cnámharlaigh Eile le Dwarfism
Acondroplasia e altre displasie scheletriche con nanismo
Achondroplasia un citas skeleta displāzijas ar pundurismu
Achondroplazija ir kitos skeleto displāzijos su nykštukėmis
Akondroplāzja u Displāzji Skeletriči Oħra b'Dwarfiżmu
Achondroplazja i inne dysplazja szkieletu z karłowatością
Acondroplasia e outras displasias esqueléticas con nanismo
Achondroplasia și alte displazii scheletice cu nanism
Achondroplázia a iné kostrové dysplázie s nanizmom
Achondroplazija in druge skeletne displazije s pritlikavostjo
Akondroplasia y otras displasias esqueléticas con enanismo
Akondroplasi och andra skelettdysplasier som orsakar kortväxthet

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I. Introduction and Objectives

The fight for equality and recognition of the social rights of all people with disabilities has advanced notably in recent years. Progresses are being made globally, including with the enactment of the UN Convention on the Rights of Persons with Disabilities¹, providing a framework for the establishment of common goals and the defence of their human rights. However, the needs of people with ASDD have been widely neglected so far.

In Europe, cooperation between countries has been slow, as policies dealing with social and disability rights are fundamentally national, even local. However, the European Union is becoming increasingly relevant in the field of social policies and more active with regards to disability and social rights. The development of the European Pillar of Social Rights² and the European Disability Strategy^{3,4} prove this trend of an increasingly 'social EU', providing more opportunities for cooperation and mutual learning.

These policy initiatives represent positive yet humble progress. The consequences of the COVID-19 pandemic have served as a painful reminder that the European Union is, to date, not ready to fully cooperate in terms of health, let alone on other social needs beyond labour and internal market functioning. Despite this realisation, citizens' demands for a 'social Europe' are now one of their main concerns⁵, and expectations are high in all Member States and other European countries. Clearly, institutions must quickly deliver real solutions for a fairer Europe.

Even though the European Union has made some progress on disabilities – such as the aforementioned Disability Strategy or the Accessibility Act⁶ –, it has still failed to acknowledge the specific needs of a long neglected and stigmatised community: people with Achondroplasia and other Skeletal Dysplasias with Dwarfism (ASDD).

There is a direct opportunity to tackle common needs of people with ASDD throughout Europe. Even though many of these needs are based on national frameworks, most of the daily challenges felt by people with ASDD are common throughout Europe and could benefit from joint solutions. From fighting stigma to better access to healthcare, as well as ensured accessibility, recognition of the condition, access to essential services, education and labour, numerous changes could be achieved with a decisive action by the EU.

Unfortunately, the voice of people with ASDD is often not audible to EU policymakers whilst advocacy organisations have had to primarily deal with local issues. Against this background, ASDD advocacy organisations

are raising their voice jointly and starting to demand a long due solution: a social Europe that delivers for people with ASDD, establishing common standards, increased cooperation and providing real change.

Our ambition is that, on the basis of the common challenges identified in this consensus declaration, the EU starts acting to bring all parties up to speed and foster the establishment of real, long-lasting solutions, in the context of its wider action on disabilities. This consensus declaration makes one wish clear: that the voice of people with ASDD is heard in this historic time that will shape the future of the Social Europe.

Why a Consensus document?

ASDD are multifaceted with broad and diverse impacts that can often be challenging to address. By aligning a consensus for common action, we take the first step in advocating for strong policies on ASDD that will improve the situation at EU and national level. This document is a milestone that for the first time identifies issues of converging priority amongst European ASDD groups and proposes concrete recommendations to build better policies for people with ASDD.

How has the document been produced?

This document is the result of a multi-year exchange between European groups that represent the integral needs of people with ASDD. A Secretariat (RPP) has worked to edit and coordinate all inputs by groups as well as research and interview several experts on the matter, resulting in the policy recommendations. The work has been carried out thanks to the financial support of BioMarin and Pfizer, to facilitate the editing and drafting of the document. The authors of this document, listed below, exercised full editorial control.

WHO IS ENDORSING THIS CONSENSUS DOCUMENT?

This document has emerged from the consensus of several organisations advocating for the integral needs of people with ASDD across Europe:



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Lyhytkasvuiset – Kortväxta ry (Finland)



Association des Personnes de Petite Taille (France)



Belangenvereniging van Kleine Mensen (The Netherlands)



Palčekovia (Slovakia)



Foundation Exploring Skeletal Dysplasias Together (United Kingdom)



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II. What is ASDD?

1. ACHONDROPLASIA AND OTHER SKELETAL DYSPLASIAS WITH DWARFISM

ASDD stands for Achondroplasia and other Skeletal Dysplasias with Dwarfism. These are a group of more than 450 rare conditions associated with generalised disorders of cartilage and bone, causing varying degrees of dwarfism or short stature⁷. This stunted growth velocity in the bones (and not in vital organs) also leads to some key morbidities.

+450 Skeletal Dysplasias

More than 1 in every 20.000 live births

Achondroplasia is the most commonly occurring skeletal dysplasia, with an approximate frequency of 1 in 20,000-30,000 live births⁸. Although most cases present at birth, some are diagnosed during their early infancy. Newborns often have relative macrocephaly, frontal bossing, narrow thorax relative to the abdomen, rhizomelia (short upper limb) and brachydactyly (short hands)⁹. The condition is inherited as an autosomal dominant manner with up to 80% individuals having parents with average stature, thus 90% of children with achondroplasia have no record of the disease in their families.¹⁰ It is caused by a FGFR3 (Fibroblast Growth Factor Receptor 3) heterozygous pathogenic variant, which encodes linear bone growth¹¹. Achondroplasia does not usually cause deficiencies in mental abilities. However, other than the disorders mentioned, it can

have additional health-related complications such as obstructive sleep apnea, middle ear dysfunction, kyphosis, and spinal stenosis.

There are more than 450 skeletal dysplasias that cause short stature¹², ranging from more common to extremely rare. The prevalence of each skeletal dysplasia depends on genetics and varies across countries. For instance, in Finland, the most common – even more than achondroplasia – is diastrophic dysplasia¹³, as it is calculated that 1-2% of population carries the gene¹⁴. Other common ones around the world are cartilage-hair hypoplasia¹⁵, hypochondroplasia¹⁶, and many others¹⁷. The physical effects and morbidities associated with them varies in each case, and so do the genetics involved, but all of them cause restricted growth in the individuals.

2. WHY ASDD?

Although in the past decades diagnosis methods have allowed to distinguish achondroplasia from other similar conditions¹⁸, historically the term has been associated to refer to all individuals with restricted growth. Secondly, the terms "dwarf" and "dwarfism" have also been used to refer to people with these conditions, alongside other stigmatising and offensive terms that are being phased out.

A.S.D.D. = Achondroplasia and other Skeletal Dysplasias with Dwarfism

However, by employing the holistic term ASDD (for "Achondroplasia and other Skeletal Dysplasias with Dwarfism"), we avoid an unintended exclusive focus on stature. We believe that the societal perception should not focus on stature, as this prevents us from talking about other issues –such as social rights and broader healthcare needs– and further stigmatises people with ASDD.

This way, we portray a balance between both concepts and make it recognisable to the public, whilst keeping an objective and scientific spirit.

ASDD is therefore an all-encompassing, neutral term that refers both to the scientific perspective and nature of these skeletal dysplasias, as well as the socially identifiable terms.

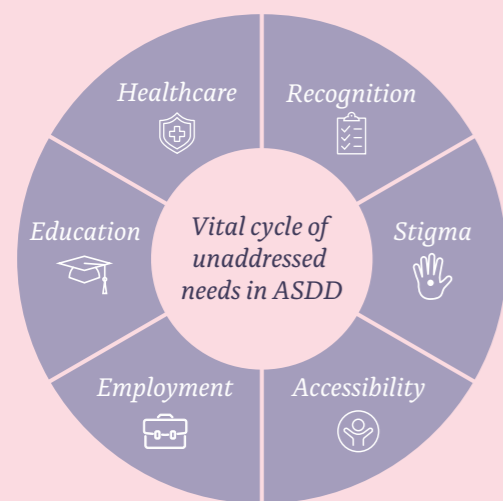
In turn, the term ASDD aims at becoming the most appropriate way of referring to all people with these conditions, from a social yet neutral point of view. We firmly believe that a balanced understanding of the conditions, starting by using the term ASDD, is also the key to unlocking real and effective equality across the world.

III. Executive Summary

There are a number of challenges that are common for people with ASDD across countries. This consensus document highlights them and puts forward key policy recommendations to solve an existing widespread neglect.

Five key topics have been identified. The first, cross-cutting issue is stigma, which still occurs and has a spillover effect into many areas of personal life. However, from a life course perspective, the first challenge is to reach an adequate and timely recognition of the condition in order to access a comprehensive set of services that support the individual and their families. Among these, accessing proper healthcare is a priority: ASDD is not only a matter of short stature, but health implications are many and varied, which need to be addressed. As with other disabilities, accessibility to spaces, products and provision of services is essential from early age – nonetheless, the neglect of ASDD in disability policies is striking. Finally, access to education and employment are also vital needs that ought to be specifically addressed and are still challenging in most countries.

Following this vital cycle, the following recommendations and call for actions addressed at the European institutions, as well as at national and local authorities, emerged as key takeaways from this consensus:



Social stigma and its consequences



- Promote political and public discussion on the need to identify and prohibit abusive practices by understanding the root causes of the inclusion of people with ASDD.
- Create publicly available benchmarking tools for reporting abuses so that authorities have information on the real impact of stigmatisation of people with ASDD.
- Combat pejorative and discriminatory social narratives publicly as a basis for improving knowledge on ASDD and promoting positive policies, developing strong regulatory systems and good guidance.
- Enact proactive policies that deepen prevention and social awareness, by directly promoting and supporting information as well as inclusive language and content campaigns by the media and public institutions.

Recognition of the condition and access to essential services



- Increase the involvement of public institutions from the initial stages, to ensure that children with ASDD are cared for according to their needs and that families are properly supported, including the development of early care guidelines and specific training on ASDD in social services teams.
- Make recognition processes to access social protection systems agile, proactive and automatic. Once the condition is diagnosed, social services should address the family's challenges and automatically recognise a range of basic benefits, without the need for the family to prove their situation.

- Strengthen the role of cross-cutting assessment teams capable of proposing comprehensive solutions for people recognised as having ASDD, with clear and updated recognition criteria.

Right to healthcare, early and adult care



- Promote greater knowledge on ASDD to enable primary care physicians and paediatricians to quickly refer children to appropriate specialists.
- Promote and prioritise early diagnosis taking into account both clinical and radiological assessment and genetic testing.
- Establish comprehensive reference centres in all countries, with the extended support of existing European Reference Networks, to achieve widespread access to early care for children with ASDD.
- Foster specialised training and the development and dissemination of uniform clinical protocols on ASDD, to clarify and standardise the guidelines for early action in any medical centre so that any person with ASDD in the EU enjoys the fastest and most accurate care possible, regardless of where they live.
- Establish knowledge exchange mechanisms between countries through international networks and joint research programmes, to foster mutual learning. A better understanding of ASDD translates into improved quality of life.

Accessibility to spaces, products and services



- Encourage the design of universally accessible spaces, including requirements for full accessibility of people with ASDD.
- Improve accessibility by the use of tools such as the promotion of good practices, the provision of incentives for companies to carry out adaptation of public spaces, or the creation or specialised working groups to assess a more diversified range of products and services.

- Include financial incentives for the development of adapted products and services in order to facilitate access to basic goods and prevent undue financial burdens.

Equal education opportunities



- Remove spatial barriers and adapt educational furniture and materials, as well as promote innovative forms of teaching based on digital media, in order to overcome obstacles that make a big difference for students with ASDD.
- Develop and disseminate educational guides on ASDD for schools and educational staff to ensure that professionals have access to official information, which will enable them to know and deal appropriately with the student with ASDD.
- Create tools to identify bullying situations and support the work of representative organisations in their efforts to raise awareness in schools by funding campaigns and communication materials on inclusion.

Support to employment and labour market



- Make available reporting and monitoring tools on discriminatory practices at work to identify discrimination cases and to collect data on the characteristics and psychosocial needs of people with ASDD in relation to their educational and occupational development.
- Support public information and awareness campaigns that promote the hiring of people with ASDD and the elimination of stigmas and popular misconceptions about the ability of people with ASDD.
- Promote regulations and best practices on labour inclusion of ASDD.

IV. Key Priorities for EU action on ASDD

1. SOCIAL STIGMA AND ITS CONSEQUENCES

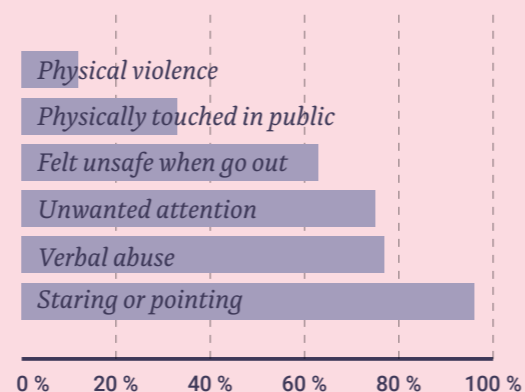
ASDDs are not only a range of health conditions, but also disabilities with a strong social burden behind them. This consideration is fundamental to defining and overcoming current challenges for people with ASDD. The pervasiveness of mockery and contempt of these people in many social contexts, due to their physical features and short stature, creates an environment of constant stigmatisation with numerous challenges for daily life. Aside from health considerations, stigma is therefore the most wide-reaching challenge which is at the heart of all other barriers for people with ASDD. For that reason, this paper looks to first address the topic of stigma, as its reduction is key to ensuring better lives for people with ASDD.



For many people with ASDD, the influence of their physical condition on their self-perceived body image, which does not conform to the socially shared standards causes diminished self-esteem and vulnerability. This is particularly true when compounded by other variables, such as lack of education, isolation, and mobility difficulties¹⁹.

Consequently, it is essential to stress that social stigmatisation of ASDD constitutes a clear precursor of interpersonal rejection and discrimination²⁰, which are manifested especially in education and employment. To combat this, public administrations adopt anti-discrimination laws and policies. There are also important initiatives to ban certain activities that specifically undermine the dignity of people with ASDD (e.g., campaigns to ban degrading shows such as the "Bombero Torero" in Spain or "dwarf-tossing" discussion in France). However, there is still much work to be done in advocating for their rights.

Events like the one described above are not old anecdotes, nor are they unique, as people with ASDD continue to suffer from abuse.



In a study conducted by Tom Shakespeare and other researchers²², it was reported that 96% of people with ASDD experience staring or pointing²³; 77% have been on the receiving-end of verbal abuse; 75% feel they often attract unwanted attention; 63% have often felt unsafe outside; 33% have been physically touched by people in public; and 12% have experienced physical violence. This situation is even more extreme in small social spheres (school, work or small towns²⁴), where the lack of diversity makes the difference in physical characteristics more keenly felt.

Moreover, demeaning practices such as 'dwarf tossing'²⁵ persist. Still, many show-business enterprises offer the use people with ASDD as a main attraction based on degrading their physical conditions²⁶.

PERSISTENCE OF STIGMA AND CULTURAL BIAS

Martin Henderson, a 37-year-old man from Wincanton, was celebrating his birthday in a pub in 2012 when a man grabbed him and threw him to the ground, falling with a heavy impact²¹. Mr. Henderson (1.3m tall) was thrown from a height of approximately 1m by his attacker. As a result, he was seriously injured and his spinal stenosis worsened, causing him serious long term mobility problems. Worst of all were the moral damage and the incredulity of having been attacked in such a brutal way, which left him with permanent psychological consequences such as fear of leaving his home.

✗ Shows, sports and other practices that in nature violate the dignity of people with ASDD persist and influence stigmatisation.

✓ It is urgent to promote political and public discussion on the need to identify and prohibit abusive practices by understanding the root causes of the inclusion of people with ASDD.

Among the root causes of this situation, popular culture has traditionally associated the image of people with ASDD with models or stereotypes linked to entertainment or mythology. The characterisation of people with ASDD in films, TV series and books as humorous or magical characters continues today and contributes to the surrounding halo of stigma²⁷. Harassment experienced by people with ASDD is fuelled by how media and advertising depict it, as we can still find numerous examples of demeaning expressions and overexploitation of the image of people with ASDD to attract an audience by mocking the condition.

The way ASDD conditions are culturally (mis) represented can affect how they are understood and, subsequently, how people are treated within society. Understanding the root causes, forms, and consequences of stigmatisation can help us overcome it.

Worryingly, as highlighted by ASDD representative organisations, many of these attacks go unnoticed, either because of a lack of reporting on the form and impact of stigma on the daily lives of people with ASDD (e.g., data on staring, abuse, etc.) or due to a persistent normalisation of these behaviours. Indeed, the physical characteristics of people with ASDD are a differentiating factor that makes this group the target of many pejorative narratives.

"Dwarfism is a disability, but a disability that is acceptable to laugh at and is actively encouraged within the media. Laughing at dwarfism for entertainment purposes is a social construct that needs to be changed." Erin Pritchard.

This situation hardly occurs in other disabilities²⁸, partly as they can be less perceptible, partly because there have been greater efforts to raise awareness in more

common disabilities than for ASDD. Lack of awareness and scarcity of statistics result in a striking lack of knowledge and prevents the development of evidence-based policies.

✗ Most people with ASDD experience physical and/or verbal abuse in their daily lives, but there are not enough specific data and reporting. The lack of visibility leads to the absence of adequate policies to tackle it.

✓ There is a need to create publicly available benchmarking tools for reporting abuses so that authorities have information on the real impact of stigmatisation of people with ASDD.

Language matters too. Slowly but surely, certain terms referring to people with ASDD strictly by stature (e.g. midget) are being phased out. This way, connotations strongly rooted in society are avoided as defining factors. This direction is in line with the current understanding of disability in the European Union, which advocates for references such as "people with disabilities"²⁹ instead of "disabled" or "handicapped".

In some countries, such as Spain³⁰ or the UK³¹, there are government guidelines on language do's and don'ts describing disability. Most countries have regulatory bodies that fight against degrading advertising and media content, as is the case in UK, where broadcasters³² do get reprimanded³³ if using offensive language or stereotypes of disability. However, there is evidence that standards are routinely ignored by some media. Moreover, a still too common amending practice is the mere apology only after intense pressure by advocacy organisations.³⁴

An advert which showed three dwarves struggling to reach a men's urinal has led to a reprimand for the makers of a cigar brand.³⁵

The Advertising Standards Authority of the UK had to ban a recruitment ad run by a casino club for "door dwarfs" in the London Underground.³⁶

✗ In many countries there is not a sufficiently comprehensive legal approach to prevent behaviours that attack the rights and image of people with ASDD, which extends stigma and its consequences.

✓ It is essential to combat pejorative and discriminatory social narratives publicly as a basis for improving knowledge on ASDD and promoting positive policies, developing strong regulatory systems and good guidance.

LACK OF PUBLIC AWARENESS AND INSTITUTIONAL SUPPORT IN COMBATING DISCRIMINATION

The lack of prevention policies has forced advocacy organisations to get involved in the most extreme stages –i.e., in legal proceedings– when attacks or undesirable behaviour occur. Advocates often face a lack of resources, either due to the lack of legal protection and solid grounds for suing, or due to missing financial and human resources.

In 2002 the French advocacy organisation APPT took legal action against TV network Canal+, in response to the following statements made during a show: "People with low mental disability are like shrimps, everything is good but the head is not; we don't say little people, we say ridiculous people".

In one instance, a Bulgarian TV show repeatedly talked about two sisters of short stature with extremely low income and intellectual capacity to watch the show, mocking their situation. Advocacy organisation LPB turned to the Electronic Media Council state authority, in charge of monitoring media contents. In turn, the authority held an emergency meeting and ordered the programme to stop broadcasting this and similar stories.³⁷

As the previous examples show, even in contexts with theoretical legal protection against discrimination, failure to effectively enforce it in a preventative way makes it necessary for advocacy organisations to run costly legal and administrative proceedings to fix the wrongdoings.

In Spain, advocacy organisation ALPE worked on several campaigns³⁸ at EU and national level, including a report together with the Ministry of Social Affairs on discrimination of people with ASDD. Public support was also reflected in the banning of demeaning shows such as the "Bombero Torero".³⁹

The French APPT has participated in several trials against discriminatory practices, such as the "arret de morsang sur orge"⁴⁰, to claim the stop of the "dwarf tossing" practice in France. The case reached the High Commissioner for Human Rights in the UN, who ruled that the French decision to ban such shows was a necessary measure to promote public order, including considerations of human dignity.⁴¹ APPT also organised a roundtable with politicians, associations and healthcare professionals in May 2021, to address the topic "For a better inclusion of small people in public policies and in society".⁴²

✗ The existence of humorous, mythological, or entertainment-related narrative patterns has the effect of normalising certain stereotypes linked to people with ASDD. The lack of social awareness leads to harmful behaviours towards them.

✓ It is urgent to enact proactive policies that deepen prevention and social awareness, by directly promoting and supporting information as well as inclusive language and content campaigns by the media and public institutions.

The lack of specific policies and effective public action to combat stigmatisation has also led to private individuals speaking out against the injustices suffered by people with ASDD. There are social awareness campaigns and blogs that try to inform from a personal perspective, as well as examples of good practices. Other behaviours and activities with wide public impact, such as the production of series and films that portray people with ASDD in a realistic and truthful manner, as well as the refusal of some writers to use language that may be considered offensive⁴³, should be equally encouraged.

Steph, a woman with a rare form of dwarfism, promotes the blog Hello Little Lady, a platform that aims "to celebrate and give a voice to those of us in the dwarf community" in which she gives information, recommendations and writes about personal experiences⁴⁴.

#WeStandWithQuaden was a worldwide response in Twitter to support Quaden Bayles, an Australian 9-year-old with achondroplasia that suffered bullying at school because of his condition⁴⁵.

What can the EU do?



There is a need for greater involvement of authorities and policymakers, both at European and national level, in the debate on the needs of people with ASDD in order to adopt solutions with real impact. The development of proactive policies that deepen prevention of bullying and abuse, social awareness and effectively punish discriminatory practices, especially when they come from media whose messages are widely disseminated and influential, is crucial.

In addition, authorities should enhance the role of representative organisations and foster their efforts by supporting awareness-raising campaigns.

At the same time, they must ensure that representative organisations have the resources to participate actively in the design and implementation of relevant policies.

The European Union institutions have the opportunity to include specific provisions on ASDD in disability awareness campaigns and projects. The new EU Strategy for the Rights of Persons with Disabilities 2021-2030⁴⁶ provides an excellent framework to plan effective activities to fight stigma, as it aims to expand the scope of disability policies by adopting an intersectional perspective that considers "the diversity of disability". In this regard, the announced creation of a Disability Platform to collect data and good practices provides a unique opportunity to give impetus to traditionally neglected disabilities, such as ASDD.

Moreover, the development of common guidelines can be fostered by the European Commission by means of joint actions. The identification of stigma towards ASDD can be legally tackled on par with the European Commission's initiatives on justice and hate speech⁴⁷, in cooperation with the Council of Europe⁴⁸, as well as with the inclusion of mechanisms of positive action in potential policies, such as the proposed Equal Treatment Directive⁴⁹ to extend antidiscrimination measures beyond the employment field.

2. RECOGNITION OF THE CONDITION AND ACCESS TO ESSENTIAL SERVICES

Once a child is diagnosed with a skeletal dysplasia with dwarfism, he or she will face a series of needs not only in terms of health but in all aspects of life⁵⁰. Reducing the existing barriers requires institutional recognition so that the person can enjoy a normal life without experiencing limitations in their social rights.



The action of public authorities takes place in two stages:

- First, they must recognise that the person has a disability and inform about the provided support, through an official 'recognition' of the condition that should be agile, informative, and holistic.
- Second, once recognised, the social protection system must ensure that the person with ASDD effectively receives the necessary social and health support, through an appropriate multidisciplinary assessment.

In this line, most European states directly or indirectly recognise ASDD conditions and have protection systems in place. However, access to these remains a barrier for many, and lack of coherent protection generates undesirable inequalities amongst the population.

The primary objective of social protection policies on ASDD should be to reduce the limitations faced by people with the condition so that they can live independently and on an equal footing with the rest of the population, enjoying all social rights to the full extent.

RECOGNITION SYSTEM: LACK OF INFORMATION AND DEFICIENCIES IN EARLY CARE

The recognition of an ASDD condition after clinical diagnosis begins with the awareness of the child's own family about the care and needs of the infant. In many cases, this process is lonely and stressful, mainly due to the great ignorance and uncertainty surrounding ASDD⁵¹.

In Spain, the Ministry of Health conducted a research on professional procedures, experiences and needs of parents when they are informed about their child's disability.⁵²

Finnish researchers are conducting the study "Towards an ICF-based self-report questionnaire for people with skeletal dysplasia to study health, functioning, disability and accessibility"⁵³. The aim is to extend the study to other EU countries in the coming years.

As such, early care is often neglected or insufficient, due to the lack of information and of personalised attention, which is related to the absence of multidisciplinary teams capable of understanding the child's and family's needs from the earliest stages of life. Therefore, there is a widespread perception of a lack of support, as shown by national surveys⁵⁴.

This situation requires greater involvement of associations at all levels. Currently, representative and advocacy ASDD organisations make up for these needs, carrying out an important task of collecting data, accompanying and informing families particularly during these early stages, often through their own developed care processes.

The organisation Little people of Bulgaria implemented a national project on "Equal opportunities for little people in Bulgaria"⁵⁵, building a support centre that provides a range of services such as social support, psychological support, rehabilitation and occupational therapy for people with ASDD.⁵⁶

The Spanish organisation ALPE has developed a professional care network in order to provide free expert advice on ASDD.⁵⁷

✓ It is necessary to increase the involvement of public institutions from the beginning, to ensure that children with ASDD are cared for according to their needs and that families are properly supported. To this end, the development of early care guidelines and specific training on ASDD in social services teams is recommended.

Moreover, diagnosis of an ASDD condition does not necessarily equate to institutional 'recognition', in the sense of accessing the social protection system. Parents or guardians of a child with ASDD face complex bureaucratic processes to prove the existence of a disability that justifies inclusion in these systems⁵⁸.

✗ The process of institutional recognition of the condition suffers from a lack of knowledge and availability of multidisciplinary teams, resulting in families having to appeal against decisions on the degree of disability recognised or to undergo burdensome bureaucratic processes in order to access certain benefits.

✓ Recognition processes to access social protection systems must be agile, proactive and automatic. Once the condition is diagnosed, social services should address the family's challenges and automatically recognise a range of basic benefits, without the need for the family to prove their situation.

LACK OF A COMPREHENSIVE ASSESSMENT FRAMEWORK

The assessment of the disability degree usually depends on pre-determined criteria related to the severity of the consequences of the condition, but not on the condition itself. As a result, the increase in the disability percentage due to other potential clinical complications is not considered. This is based on a misunderstanding of the ASDD conditions, which can only be correctly assessed through a holistic approach⁵⁹.

In the Spanish system, the diagnosis of ASDD does not entail per se a degree of disability. Further to this, the specific conditions are not recognised in the official scales. This implies that, during the assessment of a person with ASDD, clinical manifestations attributable to the alteration of other organs and systems not included in the specific chapter on the assessment of the condition which combined would increase the percentage of disability, are not usually taken into account⁶⁰.

Even when the system does promote comprehensive recognition of the condition and allows people with ASDD to be granted more extensive specific protection (as posed in the UK Equality Act of 2010⁶¹), thresholds for eligibility for benefits can be difficult to reach. This can lead families to endless appeals processes against the recognised degree of disability⁶².

Further to this, in some instances the recognition criteria is not based on medical aspects or daily life consequences, but on a certain stature alone. Needless to say, a specific height threshold can be extremely discriminatory as it disregards the nature, consequences and broader context of the disability claim.

✓ Authorities should strengthen the role of cross-cutting assessment teams capable of proposing comprehensive solutions for people recognised as having ASDD, with clear and updated recognition criteria.

INEQUITY IN THE RECOGNITION SYSTEM BETWEEN AND WITHIN STATES

The inequity in the system of recognition between and within countries, with regional disparities affecting the protection received by people with ASDD, is one of the main issues to address, particularly in decentralised countries. Even when the criteria for recognition of disability are set at national level, assessment teams and resources can be regional decisions, resulting in inequalities in the protection provided within some countries.

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In the Netherlands, some regional differences in the recognition system can cause disparities across nearby territories. As put by an ASDD representative, "a person with ASDD who lives in Amsterdam receives a financial contribution, whereas a person who lives in Utrecht doesn't."

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In France, the Maison Départementale des Personnes Handicapées (MDPH) is responsible for the assessment of disability as well as the implementation of human or technical assistance within each region. "The fact that the recognition of disabilities is managed by region is linked to the fact that the budget provision for benefits depends on each region too."

SOCIAL PROTECTION: LACK OF A HOLISTIC APPROACH

Once recognised, support provisions vary substantially between territories. In order to analyse this problem from a European perspective, it is worth noting the complexity and variety of measures provided by the authorities. In most countries, there are no planned specific services which are tailored to people with ASDD. Very often, in the eyes of practitioners in condition assessment and social services, the problems of persons with ASDD are reduced only to short stature. Therefore, little attention is paid to any other consequences from a medical point of view (as explained in the next chapter), which can create further barriers to performing normal activities such as grocery shopping, cooking, house cleaning... In cases where necessary, providing a social worker to fulfil these needs would be an 'extra' provision that is not considered as a core one⁶³.

It should be noted that in countries with developed rare disease programmes, ASDD conditions are better understood and better addressed⁶⁴. In other words, the greater the information and research input, the greater and better the social protection for people with ASDD. Explicit recognition as a rare disease also contributes to the reimbursement of medical expenses, which can be an essential part of social protection services.

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In France, achondroplasia is specifically labelled as a Rare disease during the recognition process and, as such, all health expenditure is totally reimbursed by the social security⁶⁵.

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In the UK, the focus is especially on financial support for people with ASDD, who may apply for Disability Living Allowance⁶⁶ for children under 16, Personal Independence Payment for adults of working age and Attendance Allowance for pensioners. This approach is not limited to educational grants or service-linked allowances during childhood, and it also complements other financial sources in adulthood - extending protection to people with ASDD who, in other countries, do not receive financial support when working.

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 A proper assessment of the needs of people with ASDD could help to build protection frameworks with appropriate provisions for each person's condition, age, and situation. Some models choose to promote public-private partnerships and guarantee people with ASDD the financing of services also in private facilities, thus broadening the picture of social protection.

What can the EU do?



The first issue that can be tackled at European level is the widespread lack of information and support for parents or guardians of children diagnosed with ASDD. The status recognition system is sometimes generic, lacking multidisciplinary assessment teams, which causes inequalities across countries and burdensome processes. The specific needs of people with ASDD are seldom properly addressed and sometimes the condition reduced to a problem of "short stature".

The European Commission should promote the creation of committees and networks of experts – beyond the clinical scope of the current European Reference Networks– to determine joint solutions and assessments on disability criteria for ASDD, in order to help social security systems harmonise the recognition criteria and ensure equality across all Member States. This needs to be coupled with an automatic cross-border recognition where needed, in the framework of current Directives and Regulations on health and disability.

Secondly, European institutions can promote monitoring and support policies for people with ASDD, who may have different and changing needs depending on age and evolution of the disability, in order to avoid reducing the role of the public system to a mere recognition of the condition.

To this end, the EU can provide effective platforms for the establishment of common guidelines recognising the specific benefits required to support people with ASDD in their daily lives, aiding social services to be adapted to the real needs.

The promotion of social support teams with specialised knowledge to provide advice to people with ASDD can also be part of a broader action on a social European Union.

3. RIGHT TO HEALTHCARE, EARLY AND ADULT CARE

The term ASDD refers to a group of health conditions characterised by musculoskeletal problems and severe short stature. They are considered rare diseases, as they affect less than one person in 2,000⁶⁷. The very definition is complex, as there are multiple medical reasons for short stature, including more than 400 hereditary diseases of the skeletal system, chromosomal alterations, hormone deficiencies and developmental disorders⁶⁸, achondroplasia being the most common form of skeletal dysplasias that cause growth defect in bones and short stature.



In some cases, diagnosis is possible as of routine prenatal ultrasound examination. Most commonly, individuals with ASDD have features beyond the short stature, such as proximal limb length disproportion, excessive curvature of the lower back, broad, short and trident-shaped hands, macrocephaly, frontal bossing, and midface hypoplasia⁶⁹.

These characteristics can lead to multiple health consequences throughout life that need holistic care, such as hydrocephalus, cleft palate, scoliosis, arthrosis and other skeletal problems, neurological affectations, and auto-immune problems. Some of those need immediate attention during the childhood, whereas others evolve with age.

✗ Just like for many rare diseases, healthcare obstacles are shaped by the common lack of knowledge of the condition, its consequences, limited therapeutic options and unclear medical guidelines.

As advocated by ASDD representative organisations, being 'short' is not a matter of height but has a plethora of repercussions on health and requires specialised knowledge. Despite the achievements in recent years, there is still a long way to go in the healthcare approach to ASDD conditions.

LACK OF GUIDELINES AND MULTIDISCIPLINARY TREATMENT

The main challenges faced by people with ASDD in clinical terms derive, on the one hand, from the difficulty of a straightforward diagnosis process as it encompasses many low prevalence pathologies and, on the other hand, from the multiple health implications due to the special musculoskeletal features.

Concerning diagnosis, even though achondroplasia can generally be detected in ultrasound (prenatal) whilst some other ASDD conditions can only be detected after birth based on multiple tests, in all cases the clinical assessment process can be exhausting, as it implies a recognition by different medical specialities. This can take a long time and uncertainty due to a lack of expertise. Most ASDD advocates also highlight the difficulties in diagnosis for families who live far from a relevant reference centre and have limited access to an expedite, comprehensive healthcare system.

✓ The promotion of greater knowledge on ASDD is necessary to enable primary care physicians and paediatricians to quickly refer children to appropriate specialists.

Early diagnosis is a priority for people with ASDD, as time is key to prevent further health problems arising from early childhood if they are not addressed on time. For instance, height deviation occurs mainly during the first 2 years and disproportion of the head size is more pronounced and dangerous during early childhood⁷⁰. Together with hypertrophy of the adenoids and tonsils, it can cause obstructive sleep apnoea and consequent cardiovascular and metabolic problems.

✓ Healthcare systems should promote and prioritise early diagnosis taking into account both clinical and radiological assessment and genetic testing.

Some physical problems can affect the child's motor skills development and learning process. For instance, bone alignment⁷¹ may be needed to allow for movement⁷². Some children also face speech development delays⁷³ and hearing issues, which require early interventions⁷⁴. In general, there may be various therapeutic options to physical challenges which can have important broader clinical impacts. Access to specialised knowledge and care in national health systems is therefore an urgent priority.

✓ The existence of comprehensive reference centres in all countries, with the extended support of existing European Reference Networks, is vital for widespread access to early care for children with ASDD.

In adults, the main problem is again difficult access to treatment, rehabilitation and medical checks, mainly due to the remoteness of reference centres. Physical pain, and especially psychological and emotional impact, are often omitted from care schemes. Cases of isolation, depression and suicide go unnoticed⁷⁵.

On the other hand, in some countries⁷⁶ there is still a lack of funding or reimbursement for treatments. Medical examinations are not covered by the health insurance fund, effectively imposing another barrier in access to treatment.

In Finland, in addition to public healthcare services, there are also many private doctors' clinics and hospitals. These services are often more costly than public healthcare services, but national health insurance reimbursements (Sairaanhoitokorvaus) can be received to cover the costs where needed. Kela, the Social Security Institution in Finland, will also reimburse medicine expenses. National health insurance can provide partial or even full reimbursements for medicines⁷⁷.

Continuity of care from childhood to adulthood is also a pressing matter⁷⁸. Most of the health consequences described above can persist in adulthood with aggravating consequences, such as pain, mobility issues, obesity, respiratory and cardiovascular diseases, and functional limitations. Often, health care systems create an interruption in care as adulthood is reached, without proper knowledge continuity and specialised attention. Due to the nature of the conditions, most specialised knowledge is held in childcare facilities, without proper knowledge transfer to non-childcare health centres and professionals.

Beyond the aforementioned health issues, and in connection to stigma as explained in previous chapters, mental health issues still stand out as a neglected area of care, with very little research so far and extremely limited coverage in most of the countries⁷⁹.

Given all the consequences and the relevance of early care, it is evident that people with ASDD require multidisciplinary and coordinated care, capable of

dealing with the condition in a comprehensive manner and promptly referring children to the specialists they need. As a result of the 'rareness' of ASDD, there is a lack of specific protocols and guidelines for healthcare professionals. In some settings, healthcare for people with ASDD is still seen as a 'taboo' topic, thus preventing specific care pathways to be developed. Healthcare for people with ASDD must follow the key principles of improving overall wellbeing and quality of life for people with ASDD, providing a personalised approach for each person, and focusing on health, not height.

✓ It is necessary for authorities to foster specialised training and the development and dissemination of uniform clinical protocols on ASDD, which would clarify and standardise the guidelines for early action in any medical centre so that any person with ASDD in the EU enjoys the fastest and most accurate care possible, regardless of where they live.

Many organisations, such as ALPE⁸⁰, have worked to develop a collection of guidelines and recommendations on how to handle health issues. There are also some sites collecting numerous guidelines to inform and standardise care⁸¹. All of these could be taken into account by healthcare systems.

The Finnish Medical Society Duodecim (Finland's largest scientific association) has developed care guidelines on skeletal dysplasias⁸², although they are still relatively unknown to local hospitals. In UK there is also an early care guide for parents⁸³ of children with achondroplasia (although it is often used as a reference for all ASDD conditions).

It is worth noting that some progress is being made in the standardisation of criteria for assessing the social and health care needs of people with ASDD. To fill the lack of instruments for specific patient-reported outcomes, Dr. Blömeke (University of Hamburg) developed the Achondroplasia Personal Life Experience Scale (APLES)⁸⁴, which provides a way for both the patient and the clinician to assess the patient's Health-Related Quality of life (HRQoL) in accordance with the ICF (World Health Organization's framework for the assessment of the health and disability of any person). This framework provides a universal terminology for the documentation and assessment of a child's life in clinical, public health, and research settings. Similar efforts should be institutionally supported for all ASDD conditions.

NEED FOR RESEARCH AND HEALTH-QUALITY ASSESSMENT

ASDD, as rare diseases, share the challenge of often being neglected in research. There is an evident and direct correlation between the lack of research and the lack of specialised knowledge⁸⁵ and reference systems as highlighted in the previous section, given that the care protocols and daily management of the disease by health professionals and families are based on scientific progress.

The promotion of public and private efforts in research is proven⁸⁶ to have a direct impact on the quality of life. Specifically, an informed approach from diagnosis would allow a breakthrough in early care. Similarly, investment in innovative treatments directly focused on the causes and consequences of ASDD would mitigate the health problems that these people face. In this regard, the importance of early child-focused research in the field of rare diseases has been a subject of several discussions at EU level⁸⁷ in recent years, throughout which many stakeholders and institutions have stressed the need to generate further evidence and develop more targeted treatments for children⁸⁸.

Beyond this, it should be borne in mind that, being such a multidisciplinary condition due to its diverse health implications (motor, respiratory, auditory, etc.), a better understanding of ASDD management would also have an impact on improving treatment of all the associated pathologies.

ASDD are rare diseases. As such, there is still a big knowledge gap regarding their management. Better knowledge of ASDD has a positive impact on the treatment of related diseases.

In recent years, learning and research on ASDD has gradually increased, including the noteworthy work of geneticists on achondroplasia assessing the developmental impacts in children, as well as research on early-stage care, neurological and respiratory issues, practical and emotional support, and main aspects of transitional care⁸⁹.

In some countries, such as Slovakia and the Czech Republic, public registers like REACH⁹⁰ have been set up to collect data on people with achondroplasia. They help public authorities and researchers to better understand the clinical aspects, incidence and epidemiology of the disease in a given location.

However, the sharing of knowledge between countries requires further expansion. The promotion of synergies between reference centres and the implementation of multi-country research programmes would amplify the impact of solutions, as well as provide a uniform and equitable response to these conditions in all countries. The work carried out by the European reference Network (ERN) BOND⁹¹ is a precursor to future advances, which need to be developed further.

Some countries are already promoting measures that can serve as examples of good practices:


In Finland, treatments and regular follow-ups of all the children with skeletal dysplasias are centralised at the Helsinki University Hospital. According to the regulation on specialised health care, surgeries of people with shortness of stature and skeletal dysplasia must be centralised, which also applies to adults. However, there are still challenges to get local hospitals to follow the act.⁹²

In France there is a multidisciplinary network specialised in bone diseases (the CRMR MOC), linked to the main reference hospitals in each city, coordinated by the Necker Hospital.⁹³ In the Netherlands, there is also a reference centre (the Centre of Skeletal Dependencies).

In the UK there are multidisciplinary skeletal dysplasia clinics aimed at childcare, such as Evelina Hospital⁹⁴ in London, the Centre for Genomic Medicine in Manchester⁹⁵, and others across the country. All of them are centralised, being coordinated by one centre, and the health outcomes in children are regularly reviewed.

✓ The establishment of knowledge exchange mechanisms between countries through international networks and joint research programmes would foster mutual learning. A better understanding of ASDD translates into improved quality of life.

What can the EU do?



ASDD conditions have a plethora of health implications throughout a life course. However, a comprehensive medical approach to ASDD is lacking in many places, resulting in delays and shortcomings in diagnosis, high turnover among specialists and prescription of partial solutions. Also, there are still problems in terms of access to diagnosis and treatment, as well as regular check-ups, due to the scarcity and remoteness of reference centres.

There are still many unknown aspects about ASDD conditions, due to their rare nature. This lack of knowledge is associated with a lack of research on the condition and on innovative therapies, hampering the effective tackling of their long-term health implications.

In this regard, ASDD conditions can be seen as paradigmatic diseases of the challenges identified during the revision of the EU legislation on medicines for children and rare diseases⁹⁶, considering the unmet medical needs, the lack of incentives to research and the difficulties in access to treatment. In light of the spillovers with many other diseases and conditions, improved research on ASDD can provide useful knowledge and serve as a blueprint for other diseases.

Current challenges could be significantly reduced with a clear push by European Union's institutions. The extension of the European Reference Networks is a primary way to foster the further creation of centres of reference at national level. At the same time, in the context of the health programmes of the EU, the establishment of expert groups and Joint Actions that host the formation of multidisciplinary teams will allow the elaboration of much needed common care guidelines, as well as joint research programmes on ASDD. In particular, the creation of a common portal for healthcare professionals and patients to share ideas, information and translated resources should be a flagship activity of the EU programmes.

4. ACCESSIBILITY TO SPACES, PRODUCTS AND SERVICES

Economic, social and environmental barriers can be among the most pressing for people with ASDD⁹⁷. Beyond a mere issue of stature, ASDD is a motor disability. Mobility problems (moving objects or moving around) affect 67.2% of people, followed by problems related to domestic life (55.3%) and personal care and hygiene tasks (48.4%)⁹⁸. Many of these issues persist due to systemic inequalities and misguided policies⁹⁹.



Looking at the disabilities associated with ASDD through the lens of societal surroundings, there are a number of environmental and social elements that can be improved to reduce or remove existing limitations. The aim should be to ensure full access to spaces and services on an equal footing with the rest of the population, by explicitly recognising the needs of people with ASDD in all policies.

While critics see adaptation of public spaces as a disproportionately complex activity, in reality most of the necessary adaptations are based on simple, multi-purpose solutions. These can respond to the challenges not only of people with ASDD but of several populations at the same time, following the principles of universal design¹⁰³.

✗ Despite people with ASDD having benefited from improved access to spaces for elderly and disabled people in general, their specific needs are not considered.

✓ Authorities should promote the design of universally accessible spaces, including requirements for full accessibility of people with ASDD.

PERCEPTION OF DISABILITY, ADAPTATION OF SPACES AND REGULATORY STANDARDS

Public promotion of accessibility has greatly progressed in recent years. Of particular importance is the EU Directive on accessibility of products and services¹⁰⁰, which looks at removing barriers by harmonising rules in Member States. However, while certain conditions are specially addressed in this act, others such as ASDD have been largely ignored due to a widespread neglect¹⁰¹. Still today, many people perceive the adaptation of spaces for people of small stature as a task of great complexity, unaffordable to cater for a segment of the population whose “only problem” is to not suit the standardised height.

ASDD have been traditionally ignored in disability policies, partially due to a misconception of the conditions as a body size issue that does not require any kind of public support.

However, some experts have suggested that indeed many urban environments cater only for the able-bodied, average-sized person, and as such public spaces are exclusionary for people who do not conform to these standards¹⁰². Even in countries where regulations have been enacted to solve this issue, many rules are unspecific or delayed in time.

We can identify a plethora of examples of difficulty in accessing day-to-day services for people with ASDD¹⁰⁴. For instance, height of toilets and sinks is hardly ever adapted and even toilets for disabled are higher for wheelchair use; there is a lack of adapted access to public transport¹⁰⁵, especially trains, railway stations and planes; there are usually no provisions to avoid lengthy queues in shops; and ATMs and other equipment are directly not accessible for people of short stature. As a result, many have resorted to technical measures to overcome some limitations, such as by using telescopic antennas to reach elevator buttons and door handles – which in many cases may lead to an increased stigmatisation of people with ASDD.

In Bulgaria, the Government encourages private companies to join programs for adaptation of public buildings (cinemas, theatres, stadiums), workplaces and personal vehicles for people with disabilities. However, resources are limited and few people benefit, as processes are difficult and few people are able to apply for funding¹⁰⁶.

In France, some of the most relevant public companies (such as SNCF, Aeroports de Paris, RATP, Grand Paris) work on the adaptation of spaces together with the main associations representing people with disabilities¹⁰⁷.

The lack of regulatory standards makes it difficult for people with ASDD to enforce their accessibility rights. Just as adaptations for people with visual or hearing impairments are increasingly foreseen in regulations (such as text-to-speech or digital aids), as well as for other mobility needs (such as wheelchair access), it is also necessary that regulations take into account the physical needs for people with ASDD (e.g., by looking at accessibility requirements where height is a parameter, either for public spaces, products or provision of services).

✓ Aside from regulatory standards, the promotion of good practices, the provision of incentives for companies to carry out adaptation of public spaces, or the creation of specialised working groups to assess a more diversified range of products and services¹⁰⁸, can also be positive tools for accessibility.

PUBLIC PROMOTION OF ADAPTED PRODUCTS AND PROVISION OF SERVICES

Beyond the adaptation of public spaces, people with ASDD also make use of certain products and services especially adapted for them. For instance, the use of adapted clothes, special apparatus for personal hygiene or the equipment of vehicles with special pedals and gadgets are common.

For instance, in the Netherlands some companies¹⁰⁹ offer solutions for people with ASDD (such as lightweight bicycles, doors with lower handles, adapted lighting systems).

In many instances, these are products and services that cover basic needs (such as clothing or vehicles) that due to the fact of being a rather ‘niche market’, sometimes are difficult to get access to. In fact, most of the necessary know-how and adaptations are provided by advocacy organisations. Moreover, in many countries the need for adapted products by people with ASDD is not recognised in equal footing as other disabilities, making it more difficult to access public support programmes.

Unfortunately, people with ASDD don't qualify for the same support as other disabilities for the adapted car provision schemes in the UK¹¹⁰. For instance, hire cars aren't provided with pedal extensions, but do exist with hand adaptations. "Most people now with ASDD don't qualify for support with driving costs or adaptations, so fund their own."¹¹¹

"In the Centre created by the organization Little People of Bulgaria, users have the opportunity to leave their clothes to help other people with ASDD and a tailor helps them remake their clothes. Also, our organization gives advice on appropriate aids, adaptations, etc."¹¹²

As a consequence, it must also be a priority for the authorities to promote adequate adaptations through specific programmes and financial support, preventing that those who need them do not face an undue financial burden.

✓ The inclusion of financial incentives for the development of adapted products and services should also be a matter of concern for public policies in order to facilitate access to basic goods and prevent undue financial burdens.

What can the EU do?



As mentioned above, the EU has taken very positive steps towards ensuring accessibility of products and services in the internal market, with the enactment of the Accessibility Act¹¹³ following a lengthy policymaking process. The new EU Strategy for the Rights of Persons with Disabilities 2021-2030¹¹⁴ also embodies a favourable step, as it reflects on “the diversity of disability, resulting from the interaction between long term physical, mental, intellectual or sensory impairments, which are often invisible”.

However, the physical limitations for people with ASDD have been blatantly absent from this policymaking debate. In the context of internal market regulations, the EU can and must therefore include explicit provisions on ASDD into an update of the Accessibility Act as well as into implementing measures of the Disability Strategy.

These provisions should be based on the introduction of universal design for public spaces, the establishment of minimum standards for essential products and services to be accessible considering height limitations, and the encouragement of the development and marketing of adapted products for this neglected market.

5. EQUAL EDUCATION OPPORTUNITIES

There is a widespread lack of knowledge about the implications of ASDD on learning and school performance, which leads to misinformed opinions about the abilities of students with ASDD. Since early life years are a crucial period for personal and social development¹¹⁵, normal school participation of children with ASDD is a priority.



Educational needs for people with ASDD generally do not entail adaptations in lessons or content¹¹⁶. Unlike in cognitive disabilities, most learning problems of students with ASDD are not related to the condition itself, but rather to the barriers –often physical– in accessing the learning resources. When physical accessibility problems are resolved, ASDD students should not present difficulties in their educational development¹¹⁷. Physical limitations, environmental conditions and personal perceptions must be addressed, especially concerns about body image, vulnerability within a peer group, acceptance, and academic achievement. Pre- and early adolescence are particularly pressing periods¹¹⁸. Unfortunately, factors related to the student's environment and emotional development, within their family and the school itself, are hardly taken into account when trying to understand this reality.

Most European countries have generally developed inclusion and study support policies. However, these are mostly for intellectual needs or are otherwise generalist, which often does not translate into clear and uniform protocols for schools. Even in countries that have reported the existence of specific protocols for adapting spaces¹¹⁹ and facilities for students with ASDD, they are found to be outdated and inadequate for current challenges. Currently, parents commonly report that it is usually up to the school to assess on the specific needs of the student and to design ad-hoc solutions, often improvising without clear guidance.

All in all, the main educational problems are:

- Lack of adaptation of school spaces and materials to physical needs of people with ASDD;
- Lack of expert knowledge by education professionals of the problems and needs derived from ASDD, including do's and don'ts in the classrooms such as necessary exercises or postures;
- Existence of stereotypes about ASDD that can make it difficult to integrate into the school environment.

LACK OF ADAPTATION OF THE SCHOOL SPACES AND MATERIALS

Spatial and physical limitations are the most basic school barriers perceived by a child with ASDD, becoming obstacles to learning and integration that go unnoticed by others but have a profound effect on the student. People with ASDD are often excluded from certain activities at school, simply because of a lack of adapted spaces and materials, which results in an added difficulty for their integration, as well as undermining self-esteem¹²⁰ by depriving them of participation in play and social activities¹²¹.

✗ ASDDs are rarely considered when designing school materials and spaces, which creates barriers and disability situations that could be avoided.

The main goal should be normalisation, by promoting adaptations that are usable for everyone and not only for the student with ASDD (for example, if the coat hanger is lowered, all of them should also be lowered). Consequently, the adaptations made to the furniture (chair, access to the toilet, washbasin, etc.) should be aesthetically integrated¹²².

The standardisation of protocols, such as for IT learning solutions¹²³, the availability of toys¹²⁴, the provision of adjustable tables and chairs¹²⁵ and other adapted materials at educational centres (such as lightweight folders¹²⁶, to avoid the burden of carrying too many books), or the provision of classrooms on ground floors, can be easy to implement and greatly help the integration of all children with ASDD. Some other interesting initiatives have been developed in recent years and can serve as a model.

In France, advocacy organisation APPT participated in 2020 in a working group initiated by the Ministry of Education to address specific policies for people with ASDD. Based on the conclusions of the group, the Ministry is currently working on the "RESEAU CANOPE" programme¹²⁷ to promote a network of content on inclusion, processes, and information and courses for teachers.

On a smaller scale, it is worth highlighting the inclusive efforts made through school-based programmes of adapting children's games and materials, which promote diversity awareness from an early age. In the UK, the use in Early Years (up to 5) classrooms of Lottie dolls, a set of dolls that include different ethnicities and disabilities, is popular. Among them, "Sinead doll"¹²⁸ is one with ASDD.

✓ Removing spatial barriers and adapting educational furniture and materials, as well as promoting innovative forms of teaching based on digital media, can overcome obstacles that are easily removable but go unnoticed by others, and make a big difference for students with ASDD.

LACK OF TRAINED EDUCATION PROFESSIONALS

A proper understanding of the needs of children with ASDD would have an impact on their integration and school results. At higher education levels, it would facilitate academic competitiveness and, consequently, labour market insertion.

However, education professionals often do not have guidelines to help them understand and manage students with ASDD. The educator's know-how at all levels is essential as it influences both the education of the student with ASDD and the behaviour of other students towards them as a role model. Some representative organisations carry out an important role particularly at the beginning of school years, organising meetings between teachers and parents. In most cases, there is no public support in the task of informing teachers, who do not necessarily have background knowledge on the matter. This is an added challenge for educators, who do not have the resources to be able to support children with ASDD, and creates a challenge for the students themselves, who may encounter both physical and

pedagogical barriers as a consequence of this lack of integration.

In Spain, the State Reference Centre for the Care of People with Rare Diseases¹²⁹ published a guideline document¹³⁰ to inform education professionals on the special needs of students with rare diseases.

Little People of Bulgaria promotes trainings for teachers, students, and parents¹³¹.

✗ The lack of available information for education professionals has a direct impact on students with ASDD, which prevents their full academic development.

✓ It is necessary to develop and disseminate educational guides on ASDD for schools and educational staff to ensure that professionals have access to official information, which will enable them to know and deal appropriately with the student with ASDD.

PROBLEMS OF EXCLUSION

Due to the lack of tools and knowledge among education professionals, there is a high dependency on special education teams, although children with ASDD do not face challenges that justify their separation from the rest of their cohort. This has consequences for the child's integration. Indeed, children with ASDD face serious problems of exclusion, being perceived as different by other students in many instances. In the most severe cases, this leads to teasing and bullying, triggering low esteem and affecting school performance. Even those children who feel that they are not different, in almost every case do confront major social problems when reaching their teenage years.

"[Children with ASDD] may meet a painful and usually unconquerable barrier in the social pressure for conformity when dating begins by other children in their age group. Their predictable exclusion may be a dramatic declaration that there is a difference and a severe one."¹³²

One of the main problems regarding this exclusion is the lack of awareness. Unfortunately, there is yet no extensive research exploring the education and schooling experiences of people with ASDD¹³³, preventing effective changes to be made.

✓ It is advisable to promote an inclusive approach both between teacher and student, as well as among students themselves. To this end, the creation of tools to identify bullying situations is useful, as well as supporting the work of representative organisations in their efforts to raise awareness in schools by funding campaigns and communication materials.

What can the EU do?



The role of the European institutions in supporting educational programmes is increasingly relevant. The promotion of policies on educational issues¹³⁴, including activities on the promotion of inclusion and prevention of school dropout, is a key area of focus that can be addressed by the promotion of specific programmes in the framework of the "Action plan on Integration and Inclusion 2021-2027"¹³⁵.

The European Commission must take into account the realities of ASDD in the area of education and promote, within its area of competence, the thorough study and issuing of policy recommendations aimed at this group, with the active participation of children with ASDD, in line with the objectives of the new "EU Strategy of the Child"¹³⁶.

The need for specific teaching and adaptation guidelines can be directly tackled through European policy cooperation, by promoting the creation of expert groups and continuing the support to ASDD advocacy organisations in all countries in their training and awareness efforts.

All in all, inclusion of people with disabilities, with a specific regard to the neglected needs of people with ASDD, must be at the centre of EU's policy cooperation on education.

6. SUPPORT TO EMPLOYMENT AND LABOUR MARKET

Many people with ASDD face problems of access to the labour market. While this is an issue shared with other disabilities, these conditions present distinctive features more related to stigma and lack of social awareness than to the performance of the day-to-day work. Despite this, European authorities have paid little attention to this situation. These needs are related mainly to:



- a) the physical pain that can become an impediment to carrying out certain types of activities that require strength or a great deal of mobility, and
- b) the lack of hiring and/or promotion (often based on an attribution of lack of ability due to prejudice).

in the organisation's hierarchy. This discrimination based on the influence of social perceptions in the workplace makes it very difficult to report and combat, which makes it necessary to promote active policies of awareness and support for victims of this "invisible" abuse.

Although anti-discrimination regulations are in place, there is still much to be done to address the needs of people with ASDD, both in terms of raising awareness and reporting malpractice. Another important issue is the need to combat the creation of jobs that denigrate people with ASDD and that constitute an attack to their dignity, incompatible with the values and principles of the EU.

✓ Reporting and monitoring tools on discriminatory practices at work are essential to identify whether the person with ASDD may be disadvantaged solely because of their height, and to collect data on the characteristics and psychosocial needs of people with ASDD in relation to their educational and occupational development.

IMPACT ON PROFESSIONAL LIFE

There is a lack of public statistics on the performance and challenges experienced by people with ASDD at work environment, aside from personal statements collected through surveys or local research¹³⁷. It is noteworthy, however, that people with ASDD have educational qualifications equivalent or higher than the general population but are more likely to be in the category of permanently sick and disabled rather than being accounted as for employment seekers.

This situation contrasts with the higher educational level that people with ASDD usually have, translating into a perception of over-qualification. Besides, despite giving strong value to employment, people with ASDD usually express dissatisfaction with their careers, feeling that the work environment and their superiors have low expectations of their potential performance¹⁴⁰.

✗ Height has a "halo effect" that contaminates all activity that a person with ASDD does or intends to do. "There is a false correlation between short stature and the person's ability to perform any activity."¹⁴¹

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 "They were twice as likely to be found in lower supervisory and technical or routine occupations than non-disabled people. They were half as likely to be in higher managerial roles, and a third as likely to be in lower managerial roles."<sup>138</sup>  
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✓ Institutions must support public information and awareness campaigns that promote the hiring of people with ASDD and the elimination of stigma and popular misconceptions about the ability of people with ASDD.

Even though people with ASDD do not necessarily experience barriers to employment in all cases, it has been shown that it is a huge challenge for these people to access jobs that match their qualifications, and human resource managers tend to unconsciously dismiss them¹³⁹. People with ASDD can also face greater difficulty moving up in the company for a mere perception of not being able to perform tasks due to their height, as they typically occupy lower levels

POLICIES OF INCLUSION AND DIGNITY

Contrary to this exclusion from work for reasons of short stature, there are sectors in which the characteristics of ASDD are purposely sought for. Numerous "dwarf" recruitment agencies still operate in the EU, offering shows where the main attraction is the appearance of the person with ASDD.

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 An event organisation company advertises: “Pick a costume and then book one of our dwarf entertainers to dress in that theme while handcuffing themselves to the victim [...] ends up having a wild dwarf attached to them. Get the chance for some amazing photos [...]”¹⁴²
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“Our organisation has encountered many cases in commercials, music videos and movies in which the goal is to make the short stature person smile like a clown, a magical character, and even a prostitute. In our country, people with ASDD have really low monthly incomes, and when an opportunity arises to make extra money, many easily agree to take a role, without thinking about the consequences for the damage they will inflict on themselves and the whole community [...]”¹⁴³
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Most ASDD advocacy organisations highlight that still many people with ASDD pursue careers in the entertainment business that exploit their physical appearance because of their difficulty of accessing other employment and, furthermore, due to the lack of well-paid jobs. This creates a vicious circle that ends up forcing people to carry out this type of work, which is considered to be diminishing for people with ASDD as a whole. This situation obliges advocacy organisations to act as an intermediate actor to help seek for employment. Organisations also are forced to raise awareness within companies, in order to convey the need to develop good practices, as no other disability is used as a means of profit with such social indulgence.

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 In the Netherlands there are guidelines regarding the inclusion of people with ASDD, as found in the Law on Prohibition of discrimination¹⁴⁴, equality in the application process, and Job Agreement and Quota of Occupational Disabilities¹⁴⁵. Also, the employer can get support from the state when hiring a person with ASDD who has the Wajong-status¹⁴⁶.
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In Spain, there are guidelines on Social Responsibility and Disability¹⁴⁷.
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In France, there is an ongoing discussion on fighting discrimination of people with ASDD in the same manner than racism. In the UK, two awareness campaigns are worth noting, the charity-led MoreThanPanto¹⁴⁸ and a campaign launched by a father of a son with restricted growth, Matthew Topping¹⁴⁹.
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Although most countries have regulations against discriminatory practices at work, all the facts mentioned highlight that more effort is needed to achieve real equity for people with ASDD.

✘ There is not enough institutional support in promoting work for people with ASDD, and no effective control over companies that hire people with ASDD for degrading purposes. This leads to erroneous social perceptions and continuous harm to the dignity of people with ASDD.

✓ There is a need for the promotion of regulations and best practices on labour inclusion of ASDD.

What can the EU do? 

The European Directive on establishing a general framework for equal treatment in employment and occupation¹⁵⁰ is a favourable basis for EU action on ASDD. Although in some cases the promotion of adaptations to remove barriers to task performance is necessary due to physical impediments, it is insufficient to address the problems of this group, as the discrimination derives from multiple causes related to stigma and prejudice.

Moreover, the European Commission and Member States should urgently implement existing calls for action¹⁵¹ to cover disability-related costs and entitlements, to promote more flexible social support, and to guarantee participation of representative organisations, amongst other measures to support employment. All these measures will prevent long-term impacts such as vulnerability and old-age poverty of people with ASDD.

Finally, the EU needs to promote cross-border campaigns for awareness-raising in the workplace that focus on the real capabilities of people with ASDD, combating prejudices that unjustifiably place them in lower positions of the corporate ladder. At the same time, providing equal opportunities for people with ASDD requires combating activities that thrive on attacking the dignity of people with ASDD, perpetuating a stigma that hinders the personal and professional development of the ASDD community as a whole.

V. Conclusion

ASDD are a group of conditions that share specific and common needs, as they are closely related to the areas of disability and rare diseases. These needs, as highlighted by this consensus document, reflect no more than one pressing objective: to reduce the limitations faced by people with the condition so that they can live independently and on an equal footing with the rest of the population, enjoying all social rights to the fullest extent.

Due to the stigmatised history of ASDD and the widespread neglect that people with these conditions have always been subject to, advocacy efforts have been difficult and mainly focused on fighting blatant situations of inequality and discrimination at local level.

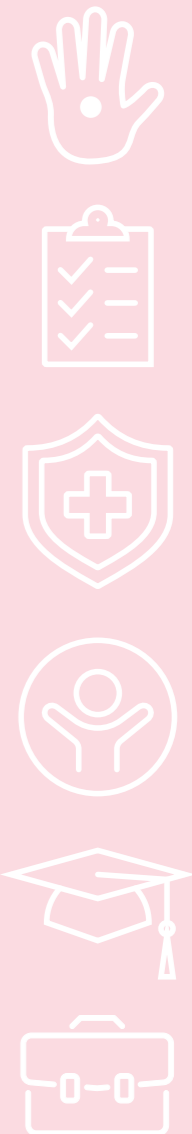
However, it is now time to stand up and raise the voice of people with ASDD. Reducing the barriers faced by people with ASDD – which are mostly common across Europe – requires proactive action by the European Union and national authorities.

In addition to the often-overlooked health problems and stigma, people with ASDD still face a set of challenges in terms of accessibility, official recognition and access to essential supporting services, healthcare, education and employment. If anything, these historical barriers have served as an extra motivation for all to keep fighting for what is just.

This consensus document provides a wide range of recommendations and actions to be taken by all involved authorities, including European institutions, in order to ensure full equality and an effective realisation of all social and human rights of people with ASDD.

This document sets a cornerstone for a unified and stronger voice internationally, one that will prevent further neglect and oblivion towards people with ASDD. From now on, policymakers and other stakeholders will be able to count on the organised ASDD community to make sure that all the needs highlighted in every of the chapters above are fully tackled.

There is no time to lose. The promotion of public policies to ensure social acceptance and integration of people with ASDD is not only a matter of dignity, but also of justice. We hope that this consensus paves the way for a future, more social Europe, that does not leave anybody behind.



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