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Parents of Children with Intellectual Disabilities for Home-school Partnership – the ELIPDA and PAT Projects

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Abstract. The European Pillar of Social Rights states that "Everyone has the right to quality and inclusive education, training and life-long learning in order to maintain and acquire skills that enable them to participate fully in society and manage successfully transitions in the labour market". The main emphasis of all education policy efforts in the European Union have been along the axis of inclusion. The UN Convention on the Rights of People with Disabilities (CRPD) and the UN Convention on the Rights of the Child (UNCRC) together define the rights and duties of the parents of disabled children as well, while clearly define the duties of public actors. The research outcomes of the ELPIDA and Parenting Together (PAT) projects – to be presented at the conference – have contributed to understanding the capacity building needs of parents of children with intellectual disabilities and that of professionals collaborating with them, also contributing to the definition of state actors' responsibilities. The two projects focused on children of different age groups and thus different needs. The evidence based ELPIDA project, had been chosen for the Zero Award 2020.

Keywords: *parents, intellectual disability, inclusion, collaboration, communication.*

European context

Statistics

There are about 100 million children in the European Union and about 80 million European persons with disabilities. While the number of children and the number of persons with disabilities is well documented, the same cannot be said of children with disabilities. The only data available concern children with special educational needs (SEN), which cover only a limited number of children with disabilities. It is estimated that 15 million European children have special educational needs. Children with disabilities combine different factors of vulnerability. As children the protection of their rights requires the adoption of special measures that are recognised by the UN Convention on the Rights of the Child (UNCRC). As individuals with disabilities, they are particularly vulnerable EU citizens who deserve specific safeguards and protection as acknowledged by the UN Convention on the Rights of People with Disabilities (CRPD).

International legislation in place

In December 2010, the European Union became a party to the CRPD. In doing so, the EU recognised the challenges persons with disabilities face in securing the fulfilment of their rights and assumed the responsibility for its implementation alongside Member States. The EU's responsibility towards the implementation of the UNCRC is of a different scale. Despite the lack of ratification by the EU, the UNCRC rights and principles guide the EU policies and action since the Treaty on the European Union (TEU) recognises the rights of the child as an EU objective.

The CRPD provides a legal framework for the protection of the rights of children with disabilities as particularly vulnerable EU citizens. Its Article 7 is specifically devoted to children with disabilities and requires Member States to take all necessary measures to ensure that children with disabilities can fully enjoy all human rights and fundamental freedoms on equal footing with other children. These obligations relate, inter alia, to the right to education and the respect for the evolving capacities of children with disabilities, the right to family life and care within the community, the right to health and access to goods and services including leisure activities. In addition, Article 16 requires States Parties to take all necessary measures to protect children with disabilities from exploitation and abuse. The EU, together with Member States in areas of shared competence or national competence, is bound by the CRPD obligations.

While the EU has not concluded the UNCRC, all the EU Member States have ratified the Convention. The UNCRC explicitly recognises the rights of children with disabilities under its Article 23. In addition, Article 2 prohibits discrimination on the grounds of disability and Article 3 calls for the best interests of the child to be at the heart of any decision affecting children, including those with disabilities. Articles 5 and 18 recognises the sole right, duties and obligations of parents for the upbringing of their children and obliges member states to provide support for parents to fulfil this role in forms they require. At EU level, Article 3 TEU defines the protection of the rights of the child as a European Union objective which requires to actively develop appropriate legislative or policy initiatives according to its competences.

European and national legislative frameworks

The current EU legislative and policy framework give recognition to the Conventions' rights and principles applicable to children with disabilities and a certain degree of implementation. However, the existing EU legislation relevant to this area is mainly sectoral (i.e., employment or immigration). The legislation addresses the situation of persons with disabilities separately from the rights of the child, whereas there is a need to consider children with disabilities as they face multiple discrimination, on the basis of age as well as disability, and to tailor measures to ensure that their rights are respected.

Member States have comprehensive legal frameworks in place reflecting the main aspects of the rights and principles identified under the CRPD and UNCRC. While it may be stated that the rights of children with disabilities are broadly recognised under national legal systems either through general or specific legislation, their practical implementation revealed to be problematic in most Member States. This is especially true in the field of supporting parenting, especially parenting support and education programmes.

The EU has no explicit competence on children with disabilities. However, the EU framework – as said before - contains provisions recognising the EU's role to promote the protection of the rights of the child as an EU objective as well as its competence to combat discrimination based on disability. Furthermore, the Charter of Fundamental Rights of the European Union, with similar legal value as the Treaties, recognises the right to non-discrimination on ground of disability in Article 21 and the rights of the child under its Article 24. This recognition, while important, cannot extend the competences of the EU as conferred by the Treaties.

No EU legal measures provide for a definition of disability. Prior to the adoption of the CRPD, in a judgment in July 2006, the Court of Justice of the European Union (CJEU) defined disability in the same sense as the CRPD within the context of employment policy as 'a limitation which results in particular from physical, mental or psychological impairments and which hinders the participation of the person concerned in professional life'.

Supporting parents

Parenting support is currently on the policy agenda of several Member States and a large COST Action, EuroFamNet is making at attempt at supporting this work by providing the necessary scientific evidence. The importance of parenting support has also been acknowledged by European organisations. In 2006, the Council of Europe issued a recommendation encouraging states to recognise the importance of parental responsibilities and the need to provide parents with sufficient support in bringing up their children. In June 2012, the Social Protection Committee adopted an advisory report on tackling and preventing child poverty which underlines the need to strengthen parenting support as part of services for children. At the 7th European Forum on the Rights of the Child, the European Commissioner responsible for Employment, Social Affairs and Inclusion highlighted the role of parenting support services in child protection and coping better with difficult situations.

Family support has been identified by research as an organising paradigm for social and public policy, so that societal well-being is more achievable if policy and services work to support families in their care-giving roles. It is perceived as a subset of activities within child-protection interventions focused on supporting parents to bring the care of their children to a safe level. Sometimes, it is also seen as synonymous with parenting support. It can have an intended focus on children's rights.

Tensions can arise in particular contexts, where family support is operationalised according to certain principles: whether its orientation is care or control, protection or welfare in general; whether the focus of support is oriented towards the parent or the child; and whether the intervention is targeted at risk circumstances or is universal in nature. A challenge within the family support orientation involves focusing on the needs of the child alongside the needs of parents, and the wider family context. However, it is by supporting the parent–child relationship, enhancing the parenting style used, and addressing issues in the wider family environment that the welfare needs of children are responded to and met.

The development of parental support policy is generally the responsibility of the national/federal government, while the implementation of the programmes through the provision of parenting support activities is, in most cases, a responsibility of the local/municipal agencies. At national level, the central authorities, such as ministries dealing with child protection, families or social inclusion issues, are responsible for the legislative framework and regulations, the drafting of national action plans and for financial support.

ELPIDA

The majority of approaches targeting issues of intellectual disability (ID) are either focused on persons with the intellectual disability (PWID) or on professionals in an effort to equip them with appropriate educational and support strategies. The need to provide parents with necessary information and skills in order to better support their children with ID is often overlooked. Parents, though, play a significant part in supporting their children to become active members of the society and to have good quality of life.

The ELPIDA project aimed to provide family members and parents of older PWID (over the age of 10) with necessary skills and knowledge in order for them to feel more confident and competent to provide support and empowerment to children of all ages with ID.

ELPIDA achieved this goal by developing a free-to-use e-learning platform, which contains six interactive educational modules providing more training, awareness raising and/or attitude change on key areas that have been identified with the active engagement of family members of PWID. These topics/areas are: Human rights, Communication, Ageing, Stress management, Transition to adulthood, and Sexual health.

The training material, available in seven languages (Danish, English, French, German, Greek, Norwegian and Portuguese), offers the flexibility of distance learning.

The partners who developed these tools believe that knowledge to be gained through this educational platform has a positive impact on the lives of people with ID and contributes to a better transition to adulthood, social inclusion, and better quality of life in general. ELPIDA aimed to create a large group of well informed and adequately equipped participants who will feel competent to support the needs of their family member with ID. Furthermore, the project aimed to create an active community of practice with high quality exchange of knowledge.

Six organizations from five European countries joined forces to produce an educational e-learning platform containing training topics/modules of interest for parents with children with ID.

At the beginning, partners with the active engagement of family members of PWID identified the key topics to be addressed.

A Needs Assessment study has been carried out to ensure that the content of the modules meet parents' needs and interest and to inform the axes for the development of platform resources, by providing training requirements. The study consists of a literature review and a pilot study – to investigate the parents' real training needs and interests through the use of a questionnaire.

At the same time a Training activity was organized where professionals from all partners obtained the necessary knowledge – theoretical and technical, and skills that enables them to produce appropriate digital resources for the ELPIDA e-learning modules.

Based on the results of the Needs Assessment study and the knowledge gained through the training activity, five of the ELPIDA partners produced modules in the area of their expertise, and the sixth was responsible for the development of the e-platform. All modules were translated in English, Danish, German, Greek, Norwegian and Portuguese.

In order to be able to assess the effectiveness and impact of the teaching content and methods as demonstrated through the e-learning platform, questionnaires were created that users/parents completed online before and after undertaking the modules.

All project results were presented in the ELPIDA Multiplier event that took place in March 2019 in Brussels.

Literature Review

The literature review was conducted in order to record the existing situation in terms of parent support and education in the participating countries – namely Norway, Denmark, Germany and Greece, as well as an overview of Europe as a whole. Short national reports were collected by partner country describing what is available to parents of PWID in terms of training and support, how this is provided and by whom. In addition to the national framework provided by project partners, a range of other resources were used such as expert interviews, review of legislation, and information from international networks to get a better and fuller picture. The most important finding is the necessity of developing parent education programmes. The lack of sufficient parent education available reinforces the need to implement projects like ELIPDA and Parenting Together.

It is evident from the reports on the national and European frameworks, despite the fact that over the last 40 years a lot of work has been done in terms of education of people with disability as well as the education of professionals, parent education and support has not been equally developed. This is particularly interesting when we take into consideration that in all participating countries it is noted that parents are the main people protecting and safeguarding their children's rights and that the education and support systems for people with disability have mainly been based on parent association initiatives. The value of family involvement in a person's transition to adulthood and towards independent living is expressed by the theory of a holistic approach in which the family plays a dominant role. At the same time, in the participating countries, there is no formal or informal procedure for certifying the family's ability to handle these specific issues. Approaches are fragmented and are based on the parent's individual anxiety and initiative, or in fragmented efforts by organizations or local authorities, municipalities, etc.

The purpose of the Social Welfare system in every European country is to support people with disabilities and to try to ensure their autonomy and their equal participation in society. It seems that in most cases, the services provided are focused on the needs of people with disability, e.g. education, housing, financial support (social benefits). Families may receive guidance and support, but they have limited access to training programmes for parents and these training programmes do not cover the whole range of topics to meet their needs. Moreover, these services often vary in quality and availability of options depending on the resources and funding of each municipality.

In addition, there seems to be a difference between the Scandinavian countries and the countries in Northern Europe in general compared to the countries in the South in terms of parent education and support as it is also the case in most aspects of the welfare system. The services in northern countries are better organised and parents are supported by a network of services that protects the whole family from the day a child is diagnosed with a disability. For example, in some northern European countries, like Norway, parents associations offer meetings, conferences and courses. These, however, are based on parents' initiative and leisure time so they do not always meet the needs of parents of people with disability. In Denmark, it is local authorities that provide the majority of parent support and training. On the other hand, the strength of the family leads most parents from the Mediterranean countries to look for and take part in expensive educational programmes in order to learn how to better support their child as free training and support is not as widely available.

In terms of the form of these educational programmes and the organisations that offer these, it is noted that most efforts are around seminars on specific topics that are developed by organisations belonging to the parental movement or often, as in the case of Germany, by the association of parent organisations. Other organisations that provide similar education programmes are local authorities, integrating them into the general lifelong learning programmes they implement.

An issue where there is no clear information on and which would be interesting to investigate in the future, is whether there is an educational package or educational modules recommended to the participating parents. When designing the ELPIDA and Parenting Together programmes, we have not found such systematic approaches.

Most educational programmes seem to be implemented by non-governmental organisations or municipalities and are offered free of charge. There are, however, specialised training programmes (e.g. SIGNET) relevant mainly to parents of people in the autistic spectrum. In fact, our literature review shows that there are several methodologies and training programmes for this specific disability available to parents, while others seem to be largely missing. These are mainly organised by private organisations and parents/participants have to pay a fee.

An area that seems to be particularly developed in both Norway and Denmark but not only in these countries is individual parent education and parent support. Whether these could be defined as counselling or education cannot be clear at this point. Finally, the lack of distance learning, e-learning etc., is also evident. Although this educational approach has been showing tremendous growth in recent years, according to our research and the information provided by project partners, there is a lack of distance learning programmes for parents of people with disability. It would be interesting in the future to carry out a research study investigating in depth and with scientific objectivity the above observations/findings. We believe that such research would help improve education, quality of life and daily life of people with disabilities and their families

Needs Assessment Study

The main objectives of the study were to gain insight on previous training/knowledge that parents of PWID already have and to explore which aspects of the chosen six topics parents of PWID need training in. The study's preparation and implementation phases spanned from November 2017 to February 2018. The sample was 167 parents from Norway (N = 51), Greece (N = 40), Denmark (N = 35), Germany (N = 22), Hungary (N = 8), Austria (N = 5) and other European countries (N = 6). Before the study, all project partners provided an overview of the planned content of their chosen topic. Taking this into account, a questionnaire was developed focusing on various aspects of the topics. The questionnaire was constructed using mainly close point Likert scale. The survey was carried out in a mixed method – some electronically, some on paper. Before the questionnaires were completed, participants were introduced the project and confidentiality was explained.

In terms of the participants' relation to PWID, the majority was mothers of PWID (74%), 17% was fathers of PWID of the participants and the rest was sibling, professionals, other family members and foster family. The PWIDs were about 50% male and 50% female, and the overwhelming majority were under 16. It is important to note that those completing the questionnaire online were more prone to be interested in participating at an e-learning course. Almost half of the participants (49%) had completed a training course prior to the study or participated in a parent group (48%)

Participants indicated that exchanging experiences, receiving information and meeting families with similar challenges are high on their interest agenda. At the same time, there is a clear priority for practical knowledge as compared to receiving theoretical knowledge. The study suggested that the planned ELPIDA training was offering parents to receive training on subjects not already provided for by municipalities and parent associations and with more practical information/advice. The focus on theories and general information in the existing parent training programmes was also documented in the literature review, highlighting the need for more practical advice. Only 24% of the participants had completed an e-learning course earlier but they indicated they would be quite interested in completing one on issues regarding supporting their child with intellectual disability (42% said they will be very interested). The small percentage of participants who had already completed an e-learning course could be explained by the small number of such courses available.

Based on these studies, the ELPIDA course was developed and offered in 6 languages. There have been 3500–4600 users per module, and the training is being sustained and available on the long term regardless the fact that the funding period ended in 2019. The programme was recognized also by receiving the ZERO Award 2020 for its contribution to inclusion of PWID.

Towards the end of the funding period, an evaluation study was carried out with 375 participants. The main objectives were to explore to what extent the e-learning platform met the needs and expectations of the participants and to explore the effectiveness of the e-learning platform at increasing knowledge level and/or changing attitudes. It was also an aim to explore ways the e-learning platform and e-learning provided to parents of PWID could be improved.

All modules attracted participants and the exit study shows that overall, the e-learning platform reached a quite large number of people who wanted to gain more knowledge and acquire new skills to better support people with intellectual disability. It is also confirmed that the majority of users accessed the material several times, going back either to complete a module or to participate in a new one.

Participants indicated that the modules improved their knowledge significantly and that the newly gained knowledge will help improve their skills. They also indicated that they feel a lot more competent in supporting their child's needs. Moreover, they did discuss what they learnt with others (parents, professionals etc.) and they did recommend this course to others. Finally, they thought it was very useful that it was available on an e-learning forms (text, videos, activities).

The exit study with participants was complemented by expert input in the final stages of the project. Interventions by external partners, especially formal education organisations such as the European School Heads Association or AEDE, the European Teachers Association at a multipler event held in the European Parliament also shows that they found it both useful and important. This will help the e-learning platform to reach practitioners, especially those working in regular, but inclusive schools and support the inclusion of students with intellectual disabilities by both widening the knowledge of teaching professionals and parents.

MEP Martina Werner (DE) (S&D) was very impressed with the ELPIDA project. She said that "a learning platform not just for parents, but for all family members ensures that children with intellectual disabilities can grow up in a supportive family environment. The inclusion of persons with physical disabilities can be achieved by adapting our infrastructure, but when it comes to the inclusion of persons with intellectual disabilities, it's important to have good supportive parenting from an early age onwards. Becoming the parent to a child with intellectual disabilities is not something you can prepare. The joy and love is often counter-balanced by moments of insecurity, often even helplessness and frustration. You never stop wondering if what you are doing is right, if you are doing everything you can to give your child the best life possible."

Renate Heinisch (DE), Member of the European Economic and Social Committee and a long-term advocate of parenting support has found ELPIDA an important tool for intergenerational learning, and also highlighted the need to also target grandparents, and not only parents with the e-learning platform.

The European Disability Forum, the umbrella organisation of disability organisations has also highlighted the importance and uniqueness of the platform. They stated that ELPIDA can help improve the living conditions of people with disabilities and their families, while respecting their rights, as advocated by the UN Convention on the Rights of Persons with Disabilities. Albert Prévos, a member of their Executive Committee, representing parents of disabled people there was highly enthusiastic about the outcomes and thus EDF readily offered their help in dissemination. He highlighted that parents of disabled children often segregate themselves from majority parent communities and thus they are difficult to reach for a number of parent organisations. At the same time, they are likely to be linked to disability organisations that in turn can make them engage in learning through the platform. EDF also emphasised the importance of reaching out to and training professionals in the health care, social and education domains.

The European Research Network About Parents in Education held its biennial research conference in Gdansk, Poland focusing on parents as power. Thus, the needs analysis and implementation reports served as a great basis for a presentation to the most important researchers in the field of parental engagement and empowerment. Apart from the very positive general welcome of the e-learning platform and the project in general, the most important message brought from ERNAPE is that they were hugely impressed by the number of visits to the platform.

Through the exit questionnaires and expert inputs, including interventions of disability organisations at the ZERO Award ceremony, it became clear that a follow up with some other topics and targeting parents of younger children would be well received. It was also understood that there is a need to specifically address professionals working with parents as well as parents of typically develop children who can act as peer advocates of inclusion.

Parenting Together – the legacy project of ELPIDA

Based on the wish and urge to continue developing tools for parents, but also to support them in the inclusion of their children, the Parenting Together project was initiated by some ELPIDA partners and including some new partners. The focus of this project is still on parents as a primary target group, focusing on the needs of parents with smaller children. As the European Disability Forum, in their praise for ELPIDA also called for more support for parents in a general context where disability programmes usually focus on independent living, leaving out the most important support network from financed innovation.

For this to be achieved, Parenting Together is especially targeting parents of children with intellectual disabilities (ID), but for inclusion to become a reality the secondary target group is the general parent and professional educator/social worker community. What we are using as a baseline in this project is the needs of parents of PWID, but also general needs of other groups that PWID are to be included into. This way, our aim is to make parents conscious of the importance of inclusion regardless of their being the parent of a PWID or not. This, in turn, will then make institutions as well as other places important in the life of children more inclusive to make a move towards universal design throughout Europe. We see a very important role for professionals in it. Thus, we are also aiming at offering them role models to better understand the otherness of PWID as well as the possibilities and advantaged of their inclusion in institutions, especially schools, for their lifelong inclusion in society.

Thus, the first aim of the Parenting Together project to establish a learning community of parents of PWID to help them overcome everyday challenges and for them to become warriors of social inclusion, and the secondary aim is to support the inclusiveness of institutions, especially of schools to create a strong base of societal inclusion of PWID, but also of people with other disabilities.

Utilising the possibilities that the digital world can offer, we are aiming at providing the information material via an e-platform to make it free and accessible to all, at any time and any place.

This project aims at providing parents of children with visible and non-visible disabilities (including behavioural difficulties) the necessary skills and knowledge in order for them to be competent and confident to provide the right support and empowerment to their children. This will have a direct positive impact on people with disabilities and will lead to better transition to adulthood, social inclusion, and better quality of life in general.

The topics, focusing on this new target group of parents with smaller children are to be around the following agenda:

- Road to getting a diagnosis
- Collaboration with professionals and development at home
- Inclusive and specialised education choices
- Universal design
- Family and community inclusion
- Parent well-being

It is of crucial importance for any child to be accepted while we are aware of traditional aversions for people who are different. The project is aiming at training advocates, and for that PWIDs and parents of a PWID will be trained for supporting the inclusion of others.

For real inclusion and the necessary support for parents to become a reality, there is a need for policy change on various levels from European to local. Based on previous experiences, the review of policies as well as the experiences working with the target group, the partners will develop an advocacy toolkit that will support the implementation and exploitation of all the programme in the partner countries and beyond the partnership. It will contain evidence-based recommendations for various policy levels as well as advocacy tools and suggestions for localised advocacy for organisations of parents as well as professionals.

The added value of international partnership for developing the programme is clear. This initial concept of this project occurred through international exchange of ideas whereby common needs where identified. The transnational cooperation increases mutual learning and facilitates innovation. Different partners from different countries will contribute bringing together their unique and valuable expertise. The project aims to provide numerous opportunities for partner organisations both during and after the completion of the project and aspires to establish long-term relationships among partners. The e-platform will be available to all parents across Europe, bringing a positive impact on quality of life to many PWID.

The main result expected form the project is the improvement of life quality of parents with young children - and through that the quality of life of the children themselves - as well as better inclusion and development opportunities for young and very young children with ID. This is expected to be achieved by parents and advocates having an impact on how institutions and other environments approach inclusion needs in general, but especially that of PWID.

The project aims to achieve this by providing the necessary knowledge and skills to parents of people with ID in order to help them be more confident and competent at offering the right support to their child. The project aims to create a large group of well informed and adequately equipped participants who will feel competent to support the needs of their families with toddlers and young children. Furthermore, the project aims to create an active community of practice with a high-quality exchange of knowledge.

The impact of the project is anticipated to be significant for all involved participants and stakeholders during and after its lifetime. All participating organizations are expected to enhance the quality and scope of their services, to create new educational materials tailored to their users' needs and to foster constructive and long-term cooperation with relevant organizations at a European level. All participating organizations have extensive networks at the national level with the community of parents who are raising disabled children (visible and non-visible disabilities), local authorities, universities, and similar organizations and also at a European level with policymakers and representative organizations like EASPD and Inclusion Europe. All the above groups can act as multipliers in order to spread the project objectives and results.

Family members and especially parents of PWID who will follow the e-learning modules, are expected to be equipped with a toolkit of resources that will empower them significantly in order to better support their children. The provision that has been made to keep the e-learning platform active after the completion of the project with all the produced modules available for free for new interested users and to enrich it with new resources, will considerably increase the impact of the project in the group of families of persons with disabilities.

Furthermore, the formation of a large group of well-informed parents, who feel competent to cope with the needs and desires of their children, will contribute to the improvement of communication between families and workers in the disability field.

Professionals and parent leaders using the case management manual and subsequently the methodology will benefit from a lifelong learning experience and will be able to use newly acquired skills that helps relieve parents of PWID and enhance the life of PWID.

Self-advocate PWID and parents will also benefit from skills and competences development through a lifelong learning experience using the training. The implementation of these skills will lead to a wider general knowledge and understanding of ID in the general population for inclusion.

Creating an evidence-based foundation

Parenting Together is still in its development stage, but the needs analysis research has already been carried out and the first deliverable, the e-learning platform for parents is available in English (and will be available also in Greek, Portuguese and Hungarian by the end of September 2022). The other tools are being developed on the basis of this research.

The first study carried out was aiming at exploring the professional support needs of parents, especially in organising and coordinating therapy for their children. It was done with parents of children aged 0 to 25, but the overwhelming majority of children are aged 2 to 8. The 53 respondents are from Portugal, Greece, Hungary, Belgium, the Netherlands and Poland. 74% of respondents think it would be useful to have professional support with coordination, but currently do not receive it. 75% would find it important that the different therapist know each other and communicate about the child's case. Regardless the lack of collaboration, 79% think that their therapists help them and their family enhance the skills and self-confidence related to the child's development and learning. It has also been explored how parents are finding and choosing the therapists for their children, and it is clear from their open-ended answers that it is relatively random and far from systematic.

The main aim of the second stidy was to involve children with ID and their parents in the development of the training material collect their personal stories promoting a positive model of diversity underpinning the positive contributions of every person in the learning process. It will lead to the creation of training, namely the online training for parents already developed and a training toolkit titled "Better together", to change negative attitudes and inform teachers and parents about the benefits of coeducation.

This study was based on focus groups organised in Greece, Hungary, the Netherlands and Portugal with the participation of a total of 20 parents and 17 children – some of them attending inclusive settings, while others special education facilities. Parents were asked about their positive inclusive experiences, strategies for inclusion used by parents and teachers, barriers to inclusion into the school and community, facilitators of inclusion at school and community level, the existing legal framework regarding education/inclusion, their views on the benefits of inclusion, and the role of interventions by others. Children's' views were facilitated using age-appropriate methodologies, in the presence of parents in most cases. They contributed with their experiences on their preferred and less preferred activities, how their needs are met and supported, perceived negative experiences and feelings, what could be changed in school, as well as participation and value of community activities.

Parents in the Netherlands indicated the usefulness of

- Providing information to parents of children without ID, deconstructing myths (e.g., referring to disability, needs, special education, rights, etc.)
- Helping professionals understand why parental engagement is beneficial and how to promote it
- Highlighting teachers' role as facilitators
- Ensuring multilingual approaches
- Sharing positive strategies (e.g., universal design for learning, assertive communication with parents, support from the community)
- Sharing about the benefits of co education
- Focusing on countries that are role models of inclusion
- Informing stakeholders about existing legislation; existing well designed continuing professional development legislation

Parents in Greece indicated the usefulness of

- Dynamic, practical examples/activities/materials
- Providing information to parents/children without IDs (e.g., characteristics of children with IDs, myths deconstruction, etc.)
- Providing information to professionals (e.g., strategies)
- Sharing other parents' experiences (e.g., excerpts)

Parents in Hungary indicated the usefulness of

- Sharing good practices from other countries
- Sharing tips for cooperation to make it easier for the parent
- Sharing tips on self-assertion and asserting your child's rights(self-advocacy)

Parents in Portugal indicated the usefulness of

- Sharing and promoting discussions among parents
- Sharing list(s) of common topics
- Providing information on the importance of inclusion for parents without ID, so they can also inform their children

- Providing information on simplifying existing legislation
- Sharing information on parents' human rights
- Sharing parents' testimonies
- Highlight what can go wrong and how to overcome these challenges

Conclusions

The ELPIDA and Parenting Together programmes have proven to be beneficial and well-received by the main target groups, and research studies verify the content and approach. It is clear that the parent empowerment and training approach is responding to a real need of parents and also a necessity to improve the quality of life of children with intellectual disabilities. It is also necessary to provide information on to not only parents of PWID, but also typically developing children as well as professionals and the typically developing children themselves about inclusion, disabilities, competences, rights, potential partnerships and collaborations, and how to support peer interactions. The Parenting Together programme is already targeting the professionals and parents, and there is space for working with children on these topics. Existing legislation is often not comprehensive enough, so there is room for advocacy on this – another goal of Parenting Together. Professionals and parents also need support in translating legislation into practice (eg. contents of professional development, human and material resources, etc.)

It is of crucial importance to acknowledge what children are interested in and listen to their voices. In the whole process, parents, teachers and also children should be considered as facilitators. It is also clear that information is not always available in depth on the benefits and common barriers of inclusion, and subsequently solutions are not always easy to find to overcome them. As a result, the benefits of truly inclusive coeducation, especially on typically developing children is not fully recognised, especially in light of curricular pressure in many countries.

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Proto negalią turinčių vaikų tėvų įgalinimas namų ir mokyklos partnerystei – ELIPDA ir PAT projektai

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Summary

Europos socialinių teisių ramstyje teigiama, kad „kiekvienas turi teisę į kokybišką ir įtraukųjį švietimą, mokymąsi ir mokymąsi visą gyvenimą, kad išlaikytų ir įgytų įgūdžių, leidžiančių visapusiškai dalyvauti visuomenės gyvenime ir sėkmingai pereiti į darbo rinką“. Pagrindinis visų Europos Sąjungos švietimo politikos pastangų akcentas buvo visų žmonių sėkminga įtrauktis. JT žmonių su negalia teisių konvencija (CRPD) ir JT vaiko teisių konvencija (UNCRC) kartu apibrėžia teises ir neįgalių vaikų tėvų pareigas, kartu aiškiai nurodant visuomenės veikėjų pareigas. Konferencijoje pristatyti ELPIDA ir Tėvystės kartu (PAT) projektų tyrimų rezultatai padėjo suprasti Lietuvos Respublikos gebėjimų ugdymo poreikius. Proto negalią turinčių vaikų tėvai ir su jais bendradarbiaujantys specialistai taip pat prisideda prie valstybės veikėjų atsakomybės apibrėžimo. Abu projektai buvo skirti skirtingų amžiaus grupių vaikams, taigi ir skirtingiems poreikiams. Įrodymais pagrįstas ELPIDA projektas buvo pasirinktas „Zero Award 2020“ apdovanojimui.

Esminiai žodžiai: *tėvai, proto negalia, įtrauktis, bendradarbiavimas, komunikacija.*

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