

Children with autism spectrum disorders and severe visual impairments: Some general principles for intervention according to the perspective of clinical psychology of disability

Journal of Public Health Research
2023, Vol. 12(2), 1–5
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DOI: 10.1177/22799036231166314
journals.sagepub.com/home/phj



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Abstract

In the last decades, an increasing number of researchers addressed the relationship between autism spectrum disorders (ASD) and severe visual impairment (SVI) (like blindness or very low visual acuity) and nowadays autism could be considered one of the most reported coexisting developmental disorders in children with blindness or other severe visual impairment. As ASD and SVI' signs and symptoms affect functioning and quality of life and different domains of functioning of children with this comorbidity, it is very important to support individuals and their families as soon as possible in the cycle of life and to promote specific interventions aimed to promote developmental potential of everyone with both ASD and VI, based on the unique balance between strengths, needs and abilities of everyone. Children and individuals with SVI and ASD and SVI are a very heterogeneous group, both about the areas of social interaction, communication, and behaviour, as well as about visual abilities and about all the other aspects of their neuropsychological and functional profiles that are influenced by their visual impairments itself, their ASD itself and the combination of them. In this paper, we aim to discuss some general principles useful to design and to develop specific interventions and to promote inclusion of children with ASD and SVI.

Keywords

Autism spectrum disorders, severe visual impairment, blindness, intervention, school, clinical psychology

Date received: 28 December 2022; accepted: 10 March 2023

Introduction

In the last decades, an increasing number of researchers addressed the relationship between autism and severe visual impairment (SVI) (like blindness or very low visual acuity) and autism could currently be considered one of the most commonly reported coexisting developmental disorders in children with blindness or other severe visual impairment.^{1–10} As ASD and SVI' signs and symptoms affect functioning and quality of life and different domains of functioning of children with this comorbidity, it is very important to support individuals and their families as soon

as possible in the cycle of life and to promote specific interventions aimed to promote developmental potential of

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everyone with both ASD and VI, based on the unique balance between strengths, needs and abilities of everyone.¹⁰ Children and individuals with SVI and ASD and SVI are a very heterogeneous group, both about the areas of social interaction, communication and behaviour, as well as about visual abilities and about all the other aspects of their neuropsychological and functional profiles that are influenced by their visual impairments itself, their ASD itself and the combination of them. There is a close relationship between ASD and SVI based on some specific aetiology at the bottom of the severe visual impairment: there are less than 10 clinical conditions where this relationship is very close, ranging from 20/30% to 70% of comorbidity (like retinopathy of prematurity, Leber's amaurosis, optic nerve hypoplasia, septo-optic nerve dysplasia, micro-ophtalmia, an-ophtalmia and CHARGE syndrome)¹⁻¹⁰; for each of these clinical condition, the just described heterogeneity of the functional profile is even more evident.

Some general principles for assessment and intervention

In this paper, we aim to discuss some general principles useful to design and to develop specific interventions and to promote inclusion of children with ASD and SVI. It is needless to say that each individual with ASD and SVI is unique, both for his/her age, history, past and current experience, as well as for his/her specific neuropsychological and functional profile related to the comorbidity between the two clinical conditions; again, he/she is unique also for the role of environment (social, cultural and physical environment) where he/she lives and interacts. According to Gense and Gense,^{11,12} each time we meet an individual with ASD and SVI the first step is 'to know the child', or saying it in other words 'to know the uniqueness of he/she' and his/her unique balance between needs and abilities, strengths, weakness and difficulties. This uniqueness is both related to unique learning characteristics and learning challenges, as well as to learning approaches and privileged ways of access to learning.¹¹ Moreover, if we consider previous learning history, we will find unique path also about strategies, tools, natural and learned accommodations, compensatory skills, assistive technologies and other resources. Then, the uniqueness is also related to the support he/she received and is still receiving from his/her caregiver/s, family, professionals and social network (formal and informal ones). From this regard, it is very important to take into account that individual with ASD and individuals with VI can have peculiar neuropsychological and functional profiles related to ASD and VI and that individuals with both ASD and VI have an ever more peculiar neuropsychological and functional profiles related to the relationship between the two disorders. It is very important the role of the neuropsychological assessment

both for the diagnosis of the ASD and SVI and for the development of treatment/intervention. With regards to assessment and diagnosis, given the heterogeneity of ASD and of SVI and its diagnostic complexity, an overall neuropsychological assessment is crucial to examine the individual's weaknesses in all the affected domains but also to examine the individual's strengths in other domains in each individual with ASD and SVI. Neuropsychological assessment is crucial both for the diagnosis as well as to design and monitor intervention and it is very important that neuropsychological professionals have had previous experiences in ASD and in SVI and on the comorbidity between them to guarantee a deeper assessment of the functional and neuropsychological profile of each individual with this kind of comorbidity. Even if a few years have passed since the first studies in the field, we are still in the first step, because relatively little research-based evidences exist on specific programmes for the comorbidity of both disorders, while there are some best practice and specific programmes based on what is known about ASDs and SVI separately and/or the experiences of teachers and other professionals who worked with both populations; further research and clinical work is needed to better explore the peculiarity of this comorbidity, aiming to develop specific guidelines and evidence-based programmes. Taking into account specifically the role of school in promoting inclusion and participation of individual with both ASD and SVI, but also in promoting his/her learning potential, we must consider that the 20th century and the 21st century saw the spread of different inclusion approaches in school in different countries.¹³ According to specific national approaches and laws/principles, students with ASD, with VI and with both ASD and VI are included in mainstream schools and classrooms or they received special educational intervention in special schools and/or special classrooms.¹³ It depends on countries and on specific national laws and approaches. Ideally, an effective educational programme in school for a student with ASD and blindness or other SVI should be based on the unique needs and abilities of the individual student and consider the core curriculum for both disabilities. Both in special classes and in mainstream classes, it is crucial that teachers and other professionals have had previous experiences in ASD and in SVI, and in the comorbidity between them, to guarantee a deeper knowledge of the functional and neuropsychological

Main goals of the intervention for children with ASD and SVI

Having in mind the framework just described which has highlighted the peculiarity of the ASD and SVI comorbidity, we now move towards the main objectives of the intervention for children with ASD and SVI and their achievement. We outline below some general principles

with which we intend to promote reflection and provide guidelines in this very complex field of comorbidities. When we consider intervention, some other aspects are then even more crucial: each intervention needs to take into account different levels and promote at least one of the following objectives: promote communication abilities, promote orientation, mobility and autonomy, support learning and developmental potential, and increase/support other cognitive abilities and general abilities/competencies useful for learning and for communicating. Last but not least, each intervention must promote explicitly generalisation of acquired skills, from the learning situation to other situations.^{11,12,14}

First, it is important to develop specific ways to communicate with children with both ASD and SVI. Children with ASD have difficulties in communication and, as an overall principle, the use of visual input could increase communicative abilities. Many of the methods generally applied for children with ASD are based strongly on images or other visual input,¹⁵ but when they have also severe visual impairments, the use of visual input could be very difficult for them. Moreover, children with severe visual impairment can access to information by other sensorial input (like tactile, proprioceptive and auditory ones), but when they have also ASD, they can have some kinds of qualitative and/or quantitative impairments in other sensorial channels that can limit/influence the use of other sensory channels.^{3,4,11,12} The use of tactile input to access to information and to communicate not always might be taken for granted. And some other specific cognitive features related to autism itself, SVI itself and the comorbidity between them might affect communication abilities, like difficulties in turn-taking, in joint attention, in the use of use of Theory of Mind abilities. Similar issues are to be considered when we talk about learning. Consequently, each kind of individualised communication and programme of intervention need to be calibrated on all these aspects; mainstream teachers, special education teachers and other professionals in the field of education and rehabilitation need to acquire specific knowledge and competences about all these aspects, with the aims to adequately communicate and support learning and developmental potentials of their students with ASD and severe visual impairments. There are some specific approaches for the enhancement of communication and learning abilities of children with ASD that are based on the known functional and neuropsychological profiles related to ASD. There are also some specific approaches for the enhancement of communication and learning abilities of children with SVI, that are based on the use of sensory channels different from the visual one. In this field is very important to distinguish between children with total blindness and children with very low vision ability. In the first situation, visual input is impossible and other sensory channels are used, in the second situation it is very important to assess the

functional use of remaining vision ability and how to use this residual visual ability to access to information. Many of the methods applied for children with total blindness are based on the use of tactile or auditory access to information and communication.^{11,12} Moreover, other methods are based on compensatory of functional academic skills, such use the use of Braille code and other communication systems, and the promotion of independent living skills, as well as the use of assistive technologies and the learning of strategies and abilities that support autonomy, basic and instrumental activities of daily living, orientation and mobility.^{11,12} Many of the methods applied for children with very low vision ability are based on the use of residual vision ability and to the use of tools of assistive technology that support visual access to information and/or permit multimodal access. In this situation, it is central the use of magnification tools and software, used of printed materials based on magnification, contrast and luminosity. Sometimes, Braille code and other communication systems are used.^{11,12} In both situations, it is very important to acquire specific information on primary and secondary learning modes, based on the specific learning style of each child. The previous mentioned methods generally used for children with only ASD and with children with only SVI are not immediately suitable when we consider a child with both ASD and SVI because the comorbidity of ASD and SVI impose specific adjustment of the methods. As we have just mentioned before, the use of tactile and auditory stimuli might not be taken for granted due to the sensorial qualitative and quantitative impairments related to autism that limit the use of sensory information; and the impairments in communication and joint attention might influence the use of some methods. Some adaptations are needed, but sometimes the realisation and the adaptation of previous methods to this new comorbidity is left to the experience of individual teacher/professional and little is known by now about their effects and effectiveness. It is now mandatory to design, develop and study new specific approaches for the enhancement of communication and learning abilities of children with both ASD and SVI.^{11,12}

Secondly, it is also important to develop specific ways to promote orientation, autonomy, and mobility of children with both ASD and SVI. SVI itself, ASD itself and the combination of both have important effect on the mobility abilities of children, specific programmes devote to the promotion of mobility abilities are crucial. For children with SVI and ASD surrounding world can be very confusing, due to the presence of a constant mix of sensory stimuli. Moreover, children with ASD and SVI might have some difficulty in using other channel sensory information to gain a coherent picture of the environment, due both to sensorial qualitative and quantitative impairments (to be hyper or hypo-sensitive to some sensorial stimuli) as well as to a tendency to use 'low central coherence'. For these and for other reasons, some methods previously used with

children with SVI to increase orientation and mobility ability, might not work well when child has also ASD. Because of some kinds of qualitative and/or quantitative impairments in other sensorial channels (different from the visual one i.e. impaired by SVI itself) and of some selective attention impairment, some traditional approaches based on the multisensory work can be difficult to use and can trigger sensory overload in children. The use of touch and hand-on hand guidance can be also difficult to use due to the same impairments in sensorial channels and to the risk of sensory overload. Overall difficulties in turn-taking and joint attention ability can negatively influence the use of co-activity that is frequently used in the mobility programmes for children and adults with SVI.^{3,4}

Thirdly, considering other cognitive and neuropsychological impairment children with ASD and SVI, a central role is played by the acknowledgement of specific impairments in executive functions and in different domains of attention. Both these cognitive abilities influence learning, communication, organisation, motivation, and the work on cognitive tasks. The need for strategies and tools that support structure, schedules, work systems and routines is mandatory.^{3,11,12} Students' problems with sensory processing, possible cognitive overload, and executive functioning, must be considered when shaping the school environment, and adapted, evidence-based ASD-practices should be applied but taking into account the need to transform visual stimuli in tactile one (or using other sensory channels).

Fourthly, in each intervention it is important promote explicitly generalisation of acquired skills and the use of an acquired skill/ability in situation different from the one where learning developed, because generalisation could be a very critical problem for children with ASD and SVI. Specific learning unit needs to be devoted to this aim.

Conclusion

In this paper, we discussed some general principles useful to design and develop specific interventions and to promote inclusion of children with ASD and SVI. We also discussed the role of neuropsychological assessment in diagnosis and in the designing of specific intervention, with the awareness that children with ASD and SVI constitute a very complex and heterogenous group^{3,4,12,16} and that, according to Gense and Gense,^{11,12} the assessment is mandatory to permit having an accurate 'picture of the learner' and to take into account this great heterogeneity. Then we discuss on some different levels and aims that are crucial in developing interventions. We are aware that we are still in the first step in this field, because relatively little research-based evidence exists on specific programmes for the comorbidity of both disorders, while there are some best practice and specific programmes based on what is known about ASDs and SVI separately. Only single specific experiences of teachers and other professionals who

worked with both populations are available. Further research is needed to better explore this topic, aiming to provide data on efficacy of specific programmes and to develop specific general guidelines to support learning and developmental potential of children with both ASD and SVI. Then specific training courses for health, school, educational and rehabilitation professionals are needed to increase professional awareness, knowledge, competencies in this fields. Specific conferences and webinars aimed to spread general knowledge and to increase awareness in public are important as well.¹⁰

Acknowledgments

Declared none.

Author contributions

All the authors equally contributed to the design of the study. They have read and agreed to the published version of the manuscript.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study is supported by the Project 'Vis à Vis', a project founded by IERFOP. The research group is composed by IERFOP, APRI SERVIZI and a research group from the Department of Education, Psychology and Philosophy of the University of Cagliari.

Consent for publication

Not applicable.

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