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Supporting Adaptive Responding and Reducing Challenging Behaviors of Children with Rare Genetic Syndromes and Severe to Profound Developmental Disabilities Through Assistive Technology-Based Programs

Editorial

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Children with rare genetic syndromes (e.g., Angelman, Cornelia de Lange, fragile X, Rett) and severe to profound neurodevelopmental and multiple disabilities may experience significant difficulties while dealing with everyday environmental requests. Beside intellectual delays, extensive motor impairments, lack of speech and communication difficulties, they may present sensorial deficits and be unable of an adaptive responding [1, 3]. Furthermore, they can be quite passive and isolated with few opportunities to profitably cope with their environment. In fact, their clinical conditions may have negative outcomes on their quality of life and they constant rely on caregivers and families' assistance [4, 5]. Moreover, they can be described with autism spectrum disorders (ASD) traits and be reported with withdrawal, tantrums, and sparse daily social interactions. Due to lack of everyday stimulation they can additionally exhibit challenging behaviors [6, 7].

Challenging behaviors are broadly defined as any behavior which may be dangerous or deleterious for own or other safety or health and may negatively interfere with a regular learning process [8]. Thus, aggression (i.e., either physical or verbal), hyperactivity, impulsivity, stereotypies, disruption constitute few examples of challenging behaviors [9]. One plausible explanation is that children with multiple disabilities are neither adequately nor sufficiently stimulated by their environment and can be motivated to provide positive stimulation by themselves [10]. However, a challenging behavior might be exhibited for communicative purposes. For instance, one may argue that attention, escape, and/or tangible items functions can be emphasized [11]. To overcome this issue a functional analysis or assessment may be useful [12].

A functional analysis is an experimental, solid, and rigorous research method helpful to evaluate the role of the challenging behavior. Typically, four main experimental conditions are randomly and systematically presented through a multi-elements baseline experimental design, namely (a) social reinforcement (i.e., attention condition), (b) positive reinforcement (i.e., tangible items condition), (c) negative reinforcement (i.e., escape condition), and (d) automatic reinforcement (i.e., control condition). Alternatively, one may use an ABC sequence, with a targeted challenging behavior (e.g., tantrums which is represented by B), an antecedent (A), with the teacher who is coming in the classroom, and a consequence (C) the teacher will modify his/her working strategy [13, 14]. That critical although not mandatory assessment is preliminary to any rehabilitative intervention program. Three basic categories are usually identified to reduce challenging behaviors, among cognitive-behavioral approach, namely (a) decelerative practices, (b) positive practices, and assistive technology (AT) [15].

Decelerative practices are commonly adopted to reduce a challenging behavior. For example, non-contingent reinforcement, extinction, response cost, time-out, mechanical restraint, saturation, differential reinforcement of other behavior can be selected, alone or combined one to each other [16]. However, that strategies do not promote any adaptive responding. From a rehabilitative point of view, it may pose ethical problems [17]. A second option is represented by positive practices. That is, prompting, modeling, shaping, differential reinforcement of an alternative behavior can be listed [18]. Next to the reduction of a challenging behavior, an adaptive responding is taught/learned first [19, 20]. The limit of such practices is that neither self-determination nor independence of the participants involved are promoted. Consequently, caregivers and parents' mediation are undoubtedly necessary [21, 22]. To emphasize an active role, one may resort on AT-based interventions [23]. AT generally include any piece, device, equipment or tool capable of enabling positive participation, favorable occupation, and constructive engagement of individuals with multiple disabilities [24]. Additionally, caregivers' burden is relevantly reduced [25]. Essentially, AT-based programs functionally fill the existing gap between the individual skills and the environmental requests. A child with a rare genetic syndrome and multiple disabilities will be ensured with an independent access to positive stimulation. A beneficial coping will be outlined

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with positive outcomes on the participant quality of life [26, 27]. A basic form of AT is represented by microswitches [28].

Microswitches are electronic sensors adapted to detect minimal behavioral responses and to provide the participant with brief periods of positive stimulation contingently through a control system unit [29]. For instance, a girl with Rett syndrome and severe to profound developmental disabilities may be fostered to an object manipulation or ambulation responses through a microswitch-based program [30]. Otherwise, communication skills may be learned through PECS and VOCA aided-strategies [31]. Within this framework, a microswitch-cluster technology is a rehabilitative strategy which pursue the dual simultaneous goal of enhancing an adaptive responding and decreasing a challenging behavior [32]. Basically, a boy with cerebral palsy and dystonic body movements may be introduced to a microswitch-cluster technology program to improve arm-lifting responses and reduce head tilting challenging behavior contingently. Next to a baseline phase in which the technology is available but inactive (i.e., no environmental consequence was delivered even if an adaptive responding was produced free of the challenging behavior), an intervention occurred. The child adaptive responding was positively reinforced contingently, irrespective of the challenging behavior. Once the adaptive responding was fostered, a cluster phase was carried out. Thus, the adaptive responding was positively reinforced only if it occurred free of the challenging behavior. Both responses were detected through tilt sensors fixed on the participant' arm and hat, respectively [33].

In light of the above description, different solutions may be envisaged. An illustrative example may be occupational and/or functional purposes. Stasolla et al., [34] exposed six children with ASD and severe to profound delays to a microswitch-cluster intervention aimed at teaching a functional activity of inserting an object in a container and simultaneously decreasing mouthing. Intervals with indices of happiness as an outcome measure of the participants' quality of life were additionally recorded. A 3-month follow-up was conducted. Sixty external raters involved in a social validation assessment (i.e., a standard procedure to corroborate the intervention clinical validity, suitability, and effectiveness) favorably endorsed the use of the technology. Results evidenced that all the participants learned the functional use of the technology and consolidated the learning process. Perilli et al., [35] proposed to six adolescents with fragile X syndrome and severe to profound delays a microswitch-cluster technology to supporting functional activities (i.e., inserting three objects in three different containers in a 4 s interval) and eliminating hand biting. An extended outcome measure of their quality of life (i.e., intervals indices of positive participation) was also considered. A long-term follow up (i.e., one year) was assessed. Sixty-six external raters positively scored the technology in a social validation procedure. Positive data were documented for all the participants involved.

This brief overview outlines that whenever a plausible customized technological solution was implemented, children with multiple disabilities could learn new adaptive responding and decreased the challenging behaviors accordingly. Their quality of life was improved and caregivers burden reduced. External raters positively considered the use of the technology. The encouraging and promising results should be interpreted with caution and new adapted technological solutions should be systematically investigated for both research and practice purposes.

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