Contributions of speech-language therapy to the integration of individuals with Down syndrome in the workplace

ABSTRACT

Purpose: To analyze the contributions of speech-language therapy in the integration of young individuals with Down syndrome (DS) into the workplace, with reference to their professionalization. Methods: A questionnaire was distributed to eight undergraduate students (tutors) who participated in a project with individuals with DS, five mothers of individuals with DS, and five employees from the institution in which the present study was conducted. The questionnaire assessed the communication, memory, behavior, social interaction, autonomy and independence of the participants with DS, called “trainees”. The trainees were employed in one of five routine work sectors at the university that conducted the present study. The data collected in this descriptive and cross-sectional study were analyzed quantitatively and qualitatively. The Research Ethics Committee of the affiliated institute approved the project. Results: Mothers and tutors rated the trainees' language skills as “good”. However, their ratings differed from those of the participating employees. After the trainees with DS were placed in a work environment, significant changes were observed in their communication and autonomy. There was no improvement in the trainees' independence, but after training noticeable changes were observed in their social behavior and autonomy. Conclusion: Speech-language therapy during vocational training led to positive changes in the social behavior of individuals with DS, as evidenced by an increase in their autonomy and communication.

RESUMO

Objetivo: Analisar as contribuições da Fonoaudiologia no processo de inserção no ambiente laboral de jovens com síndrome de Down (SD), tendo em vista sua profissionalização. Método: Foi aplicado um questionário a oito alunos de graduação, que fazem parte de um projeto de extensão com pessoas com síndrome de Down, cinco mães dos jovens participantes do projeto e cinco funcionários da instituição de origem. Os jovens participantes do projeto com SD, denominados estagiários, passaram a fazer parte da rotina de trabalho de cinco setores da universidade em que se realizou a pesquisa. O estudo se caracteriza como descritivo e transversal e os dados foram analisados quantitativamente. Resultados: Segundo os dados pesquisados as habilidades de linguagem das pessoas com SD foram consideradas boas, mas não estavam efetivas para o mercado de trabalho. Após a inserção em um ambiente de trabalho, foi visto que houve mudanças significativas tanto na comunicação como na autonomia dos sujeitos do estudo. Conclusão: Houve mudanças no comportamento social, maior uso da autonomia e ganhos no empoderamento dos jovens com síndrome de Down.
INTRODUCTION

According to the most recent census conducted by the Secretary of Human Rights in 2010, almost 24% of the Brazilian population has some type of disability\(^{41}\). Further, 23.6% of the population entering the workplace in 2010 had at least one auditory, visual, motor or intellectual disability. Intellectual disability exerts the greatest negative impact on employment, with the workplace participation of individuals with such disabilities being the least prominent.

Down syndrome (DS) is a genetic condition caused by an extra chromosome in Pair 21. Cardiac problems, muscular hypotonia, slower development, delayed language acquisition, learning difficulties and other conditions that vary according to the individual and the environment\(^{2,3}\) are very common in individuals with DS. Although there are no specific statistics on the number of individuals with DS in Brazil, it is estimated to be 270,000\(^{4}\).

Due to the aforementioned health and intellectual challenges experienced by individuals with DS, it is difficult to include them in the workplace. In addition, due to the lack of knowledge about DS and the possibilities for the development and adaptation of these individuals, difficulties are encountered in their training\(^5\).

Work is a fundamental means to exercise citizenship affording individual autonomy. Thus, in the context of empowering individuals with intellectual disabilities, we can understand that their participation in a work context would lead to a shift from their disadvantaged status and stigmatization to one in which they are seen as capable citizens with rights and responsibilities.

Several Brazilian laws promote social inclusion. Specifically, the reservation of jobs in public and private companies seeks to create opportunities for individuals with disabilities.

Law no 7,853, dated October 24, 1989, for example, established rules that ensure the fulfillment of the individual and social rights of individuals with disabilities in education, health care, work, leisure, social security, and transportation, and the compulsory registration of disabled individuals in public and private establishments\(^{40}\).

The affirmative Act for the Disabled and People with Disabilities, Law no 8,213, dated July 24, 1991, requires that a company with one hundred or more employees must fill two to five percent of its positions with rehabilitated beneficiaries or individuals with a disability\(^7\).

Law no 13,146 of July 6, 2015, states that individuals with disabilities are equally entitled to fair and favorable conditions of employment, including equal remuneration and that it is a public policy priority to promote and guarantee conditions of access and permanence for disabled individuals in the workplace\(^4\).

Such laws are fundamental to enable individuals with disabilities to secure their place in the work environment and to thereby develop their work activities and autonomy like any other citizen. However, in order to do so, most of them require habilitation and/or rehabilitation to develop their professional skills. Vocational rehabilitation is a concept that has been used by the International Labor Conference since 1991. It aims to enable the individual with a disability to obtain and retain employment, thus enhancing that individual’s integration or reintegration into society\(^9\).

In a study of individuals with intellectual disabilities, it was observed that previous planning and training related to the job in question beginning with simpler situations and moving onto more complex tasks led them to present target behaviors and to engage in decision making\(^10\).

Thus, there is a need for further research and subsequent public action because the shared characteristic of limited communication in individuals with DS directly affects their quality of life and social relationships. Further, these findings suggest that individuals with DS can benefit from speech-language therapy focused on training and refining their speech abilities, verbal and gestural expression/comprehension and reading and writing.

To improve speech-oriented work performance, speech-language therapy should focus on the range of sensitivity, tone, posture and mobility, as they relate to the phonoarticulatory organs for speech articulation (OFAS). In individuals with DS, the difficulties encountered with sucking, chewing and swallowing affect articulation and consequently expressive speech, justifying the need for speech-language interventions for these functions. A speech-language therapist working in partnership with the individual with DS and his/her family seeks to promote interaction and social communication through the development of verbal and nonverbal skills\(^{11}\).

Employment should aim to achieve autonomy in attitude and communication in individuals with DS, to eventually achieve his/her social and professional integration. In turn, this would effectively contribute to empowering young individuals and adults with DS.

“Empowerment” refers to the mobilization process of minority groups demanding their rights, with the aim of improving quality of life and increasing autonomy.

Thus, the objective of the present study was to analyze the relationship between speech-language therapy and work placement for young individuals with DS.

METHODS

The present descriptive and transversal study was part of a project conducted by the authors’ affiliated institution. The associated researchers met all the ethical requirements, and the participants involved in the study signed the Terms of Free and Informed Consent. The study was approved by the Research Ethics Committee of the affiliated institution (Opinion Number 1,302,829).

The study included eight undergraduate students (three speech-language therapists, one educator, and four occupational therapists), mothers of the five young individuals with DS who participated in the project and four employees of the institute where the project was implemented. The inclusion criteria was that the previously mentioned participants have a direct relationship with the individual with DS (henceforth referred to as “trainees”), as a legal guardian or tutor in the extension project, or as an employee in the sector in which the trainee performed their internship. Criteria for exclusion included failure to respond to the study instrument or failure to consent to participate in the procedures.

The five trainees with DS who participated in the extension project were aged from 16 to 32 years. Each trainee was...
accompanied by a tutor, a graduate student involved in the implementation of the project and an employee of the sector in which the trainee was placed. The tutor had the role of mediating between activities, the work itself and the trainee, while the sector employee assigned the tasks during the internship. Additionally, all the trainees had been receiving speech-language therapy for at least two years and they were seen weekly by a speech-language therapist within the same institution.

This extension project aimed to implement empowerment strategies for the promotion of education, health and autonomy of individuals with intellectual disabilities, with a view to aiding their professionalization. As a part of this project, the participants with DS participated in routine work in five sectors of the University. Each week, the trainees performed tasks that were assigned to them and they experienced the work routine of the sector in which they were placed.

For the present study, a questionnaire was created by the researchers based on the social-communicative aspects related to the inclusion of individuals with intellectual disabilities into the workplace. Thus, the questionnaire aimed to assess the social-communicative changes caused by the placement of the individual with DS in the work environment.

The participants answered the 10-item questionnaire that was prepared in simple and objective language. The items assessed the communication, behavior, social interaction, autonomy and independence of the trainees. Responses to Item 1-7 were made on a Likert-type scale, while Items 8–10 contained an objective (yes/no) and a descriptive section, enabling the participants to state their personal viewpoint on these issues. Participants were asked to respond according to their perceptions of the trainee with whom they had contact. Each employee and tutor answered the questionnaire referring to only one trainee, while the mothers did so for their own child.

Data collection occurred during February and March 2016, seven months after the placement of the trainees in the work environment. These data were then tabulated and organized into a digital spreadsheet. Descriptive and inferential statistical analysis was then performed.

The descriptive responses were analyzed qualitatively, using the following three steps: 1) reading the responses, 2) creating categories or groups of responses in charts; and 3) interpreting and analyzing the results according to the procedures of Discourse Analysis (DA) using a French matrix.

Statistical analyses were performed using the SPSS software, version 20.1, with significance being p<0.05.

RESULTS

The participants’ perceptions of trainees’ communication varied from “bad” to “very good” (Table 1), with most respondents reporting that it was “good.”

Regarding expression, which was evaluated with the question, “Can people understand the trainee’s speech?”, the majority of participants reported “neither agree nor disagree” (n = 10). Regarding comprehension, i.e., the trainees’ understanding of others and whether the trainees exhibited good interaction in the work environment, most participants indicated “yes” (n = 13 and n = 11, respectively) (Table 2).

In evaluating the trainees’ behavior after participating in work activities, the majority of participants affirmed that there had been some change in their social behavior after placement in the work environment (n = 14). However, most respondents did not agree that the young individuals with DS were “independent” (n = 8) (Table 3).

The results showed that, following placement in the work environment, the young individuals with DS presented greater autonomy in performing tasks (n = 15). It is noteworthy that while mothers and tutors believed that there was an improvement in this aspect, the sector employees did not report the same outcome (Table 4). Further, most respondents stated that the trainees’ communication improved after joining the project, however, there was no consensus among the participants when asked if the trainees’ language was adequate for the workplace (Table 4).
Next, the association between the role played by the respondent in the project (tutor, mother, or employee) and their answers regarding the trainees’ abilities was analyzed. These skills included communication, expression, comprehension, behavior, interaction, independence, communication after participation in work and language in the workplace. No statistical differences were observed between the three groups of respondents in terms of their assessment of these variables, except in the area of autonomy (p = 0.025), in which only the sector employees’ assessments differed (Table 4). This finding indicated the employees’ tendency to report more negative responses.

Further, in terms of autonomy, participants could also describe the situations in which the trainee exhibited greater autonomy after placement in the workplace. These responses were analyzed and categorized, the findings of which have been presented in Figure 1. Similarly, participants could describe the situations in which the trainees exhibited (or did not exhibit) changes in communication after work participation. Related findings have been presented in Chart 1.

Additionally, the tutors’ questionnaire specifically sought information on their objectives regarding the professional rehabilitation of the individuals with DS (Chart 2).

Table 3. Social behavior and independence of trainees with Down syndrome

<table>
<thead>
<tr>
<th>FUNCTION</th>
<th>SOCIAL BEHAVIOR</th>
<th>INDEPENDENCE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Disagree</td>
<td>Neither disagree nor agree</td>
</tr>
<tr>
<td></td>
<td>n %</td>
<td>n %</td>
</tr>
<tr>
<td>Tutor</td>
<td>0 0</td>
<td>2 25.0</td>
</tr>
<tr>
<td>Mother</td>
<td>0 0</td>
<td>0 0</td>
</tr>
<tr>
<td>Employee</td>
<td>1 25.0</td>
<td>0 0</td>
</tr>
<tr>
<td>Total</td>
<td>1 5.9</td>
<td>2 11.8</td>
</tr>
</tbody>
</table>

Table 4. Autonomy, post-work communication and language in the workplace

<table>
<thead>
<tr>
<th>FUNCTION</th>
<th>AUTONOMY</th>
<th>POST-WORK COMMUNICATION</th>
<th>LANGUAGE IN THE WORK PLACE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>Yes</td>
<td>P Value</td>
</tr>
<tr>
<td></td>
<td>n %</td>
<td>n %</td>
<td>n %</td>
</tr>
<tr>
<td>Tutor</td>
<td>0 0</td>
<td>8 100</td>
<td>0 0</td>
</tr>
<tr>
<td>Mother</td>
<td>0 0</td>
<td>5 100</td>
<td>0 0</td>
</tr>
<tr>
<td>Employee</td>
<td>2 50</td>
<td>2 50</td>
<td>1 25.0</td>
</tr>
<tr>
<td>Total</td>
<td>2 11.8</td>
<td>15 88.2</td>
<td>1 5.9</td>
</tr>
</tbody>
</table>

*Significance value: p < 0.05* - Chi-squared test

Figure 1. Autonomy of Individuals with Down syndrome

Caption: (A) Desire to independently engage in day-to-day activities; (B) Increase in interaction with others, such as starting conversations and overcoming shyness; (C) Greater independence in carrying out activities; (D) Increase in self-esteem and self-confidence; (E) Improvement in attitudes and simple problem solving; (F) Improvement in organization with respect to objects and space
DISCUSSION

Speech and language acquisition may be one of the major problems experienced by individuals with DS\textsuperscript{[3,12,13]}. However, factors such as stimulation from childhood and the spectrum of individual differences found in this group lead to different developmental trajectories\textsuperscript{[13]}. The present study revealed differences in the perceptions about the communication abilities of the young individuals with DS; however, the majority of respondents considered them “good.” These differences may be due to differences between the respondents themselves (Table 1).

Speech-language intervention aims to enable individuals with DS to overcome their communication difficulties\textsuperscript{[14]}. Therefore, varied resources and strategies may be used in the intervention, including the promotion of other communication means. The speech-language therapist acts as a mediator in all these processes\textsuperscript{[15]}. The degree of inclusion of individuals with DS in the workplace also depends on the continued stimulation that they receive during the infant-juvenile phase, which is considered part of a continuous process with no end as such, but having ongoing consequences in the life of an individual with DS\textsuperscript{[4]}. While the language of individuals with DS is often simplistic, the expression of tense, gender use and subject-verb relationships are commonly complicated. However, their comprehension is often more advanced, mainly in terms of vocabulary\textsuperscript{[12,16]}. The present findings corroborated these points, as evidenced by the respondents’ reports that trainee comprehension was stronger than their expression (Table 2).

The literature also reports that individuals with DS have an aptitude for relationships and interactions\textsuperscript{[17]}, which was also observed in the present study. With reference to abilities of the individuals with DS within the workplace, this would translate into the trainees’ ease in dealing with people and clients\textsuperscript{[4]}. Professional rehabilitation is often provided to individuals who present limitations and labor restrictions that continue over a long period, including, in this context, individuals with disabilities or those who experience difficulties with professional performance owing to illness\textsuperscript{[18]}. Brazil professional rehabilitation programs are implemented to help workers return to work and to offer courses for professional requalification and/or higher education. The professional rehabilitation process is initiated through the stabilization of physical health, which is linked to the Universal Health Care System\textsuperscript{[19]}. Interdisciplinary participation of different health care services; promoting assistance and support for professionalization; and promotion of collaboration between work, health care and social security sectors; are important aspects to overcome a trajectory of exclusion of individuals with disability in society\textsuperscript{[18,19]}. In this context, a speech-language therapist along with other professionals can support the rehabilitation process by helping the individual with DS improve his/her language and communication abilities in general, and by collaborating in the rehabilitation, training, mediation, and adaptation processes in the workplace.

This mediation and support in concrete and material situations should accompany the placement of individuals with DS in the workplace. The trainees’ ability to learn requires more time and...
adaptation in terms of content transmission and the quantity of activities, in order to avoid fatigue. 

In this sense, through the interventions and interpretations of the speech-language therapist, the communication skills of individuals with disabilities can be improved. Additionally, speech-language intervention can be used to increase the social participation of these individuals. Therefore, strategies are developed with the individual with disability to overcome these difficulties and to provide support, not only with a clinical but also practical focus as well to deal with the real world demands of work in this new environment.

Work is one of the ways by which individuals relate to the world, either in the manufacture of products or the provision of services based on social needs, or through the mechanism of socialization and citizenship that these processes provide. Thus, employment enables individuals to exercise citizenship and consequently affords them a degree of autonomy in through their employment.

Based on this understanding, the participation of individuals with DS in the workplace allows them to achieve a new status as capable citizens and as holders of rights and duties, leading to their empowerment. This corresponds to the struggle for democratic representation and the reduction of the vulnerability of minority groups. Empowerment therefore contributes to the development of a perception by the individual with a disability of themselves not based on their limitations or challenges, but as autonomous individuals. This leads to a conception of “difference” as something that complements him/her and does not label him/her as “inferior”.

Participants in the present study reported that individuals with DS had not achieved independence (Table 3). The same was reported by a survey conducted with individuals with disabilities in which the responses of their family members revealed a lack of autonomy in these individuals. Often, these individuals are not given credibility or a voice, which is truer in the case of those with intellectual deficiencies, since they are often “overprotected” by other individuals. Therefore, they often lose the opportunity to lead their own lives.

Many countries seek to create employment opportunities for individuals with DS. Work strategies have been created to support these individuals and to prepare them for the workplace. In the work environment, someone is often assigned to support the individual with DS until he/she has learned the necessary skills. In the present study, this function was assumed by the tutors, who declared that part of their objective was to work with their trainee to accomplish the proposed activities, always aiming for the trainee’s autonomy in the tasks, such that, over time, they may be performed by the trainee alone (Chart 2).

Once opportunities such as courses, training and knowledge extension are offered, the individual experiences greater security and an increase in self-confidence, thereby enhancing their empowerment. As a result, there may be an improvement in the individuals’ self-esteem and confidence, an awareness of having the ability to make choices in his/her life, concern for his/her equality of rights and the ability to overcome daily challenges.

The integration of individuals with intellectual disabilities into the workplace and the changes that this may entail in terms of independence and social integration plays an important role in these individuals’ lives. For them, being an employee affects their interactions and coexistence with others helping them learn to overcome barriers, enabling them to feel useful and providing them with opportunities to participate more actively in society, thereby increasing their quality of life.

Realizing changes in the autonomy of the activities of the trainees, increasing desire to participate in daily activities and enhancing performance of such activities were frequently reported as goals for the intervention. Participants also reported the trainees’ improved performance in social interactions, increased self-esteem and greater interest in activities, which demonstrates their feeling of greater independence (Figure 1).

Increased autonomy leads to changes in an individual’s behavior in the search for rights and agency. In the present study, most participants said that individuals with DS gained autonomy, but there was some disagreement in their responses (Table 4). It can be suggested that these individuals may have developed the weakest connections with the trainees, which was different from the strength of the connections established by the mothers and tutors with the trainees, making them less sensitive in identifying minor changes. Accordingly, employees, who were less likely to perceive trainees with awareness or understanding, may have expected “complete” abilities from the trainees, and therefore may not have understood “autonomy” as a greater accomplishment of tasks.

It is feasible for society to believe in and expect good performance from individuals with disabilities, but it is necessary to understand that, to enable these individuals to enter the workplace, the concept of the “ideal worker” must be reconsidered, so that the workplace is accessible to them. This, in turn, would give rise to new ideas, to the acceptance of the differences presented and to eventually generating a less exclusionary society. However, this outcome is quite difficult to achieve, since the capitalist system is based on profit, which relies on competitiveness of both products and productivity.

When comparing two groups of individuals with DS, one included in and one excluded from the workplace, those who were included showed a significantly better ability to manage their day-to-day responsibilities, communication and socialization, revealing that individuals with DS who are included in the workplace have better communicative performance in different contexts.

Considering communication and relationships with others, the actions of others are capable of establishing new possibilities for communication, leading the individual with disabilities to overcome their language difficulties. Therefore, speech-language therapists who represent “the other” need to lead individuals with disabilities to participate in shared situations.

The present participants reported improvements in the trainees’ communication after work placement (Table 4), thereby...
corroborating the literature\(^{15,25}\). Trainees began initiating conversations, there was an increase in sentence production, they began to narrate and/or explain facts or questions through oral language and they were more comfortable while speaking and interacting. It is also worth mentioning, as reported by one employee, that the change in the trainee’s communication after interaction with other individuals in the sector, revealed the influence of the social environment on improvements in communicative skills.

In this study, slightly more than half of the respondents said that the trainees’ language skills were adequate for the placement of the young people with DS into the workplace, while the remainder indicated that they did not find these skills adequate for such a placement (Table 4). Therefore, the question arises as to whether the individual with a disability must go beyond his/her developmental level to occupy a position, or if it is necessary for employers to adjust to the individual’s abilities. It is important to be aware that these two situations are not mutually exclusive and that changes are necessary in both directions. Efforts should be made to advance an individual’s linguistic abilities and employers should adapt their forms of communication when necessary. The present data showed that, although these trainees could communicate and that they exhibited improvements in this aspect, they were not yet adequately "prepared" for the workplace, since the work environment selects individuals according to their performance and values productivity.

In this regard, employee management practices and employer flexibility are fundamental for disabled individuals’ inclusion. These practices must be adapted for each worker, seeking to fulfill and valorize these two areas\(^{25,26}\). Awareness activities and actions in the workplace are also fundamental, so that co-workers get to know the individual and develop appropriate strategies when necessary, such as changing their attitude towards the individual with DS, facilitating communication, creating attitudes that favor the individual’s performance and creating an awareness of the responsibility and urgency of the tasks. Speech-language therapists being professionals who are best able to deal with the issues described, should also collaborate during this stage.

Prior to the present study, it was considered necessary to expand the scope of speech-language therapy to individuals with DS and to ensure that an understanding of such individuals’ health also permeates the aspects of citizenship, work and empowerment.

The present study revealed that speech-language therapy can be used in several stages of life of individuals with DS. The involvement of a speech-language therapist from child stimulation until the beginning of professional engagement in adulthood, would make an effective contribution to the communicative demands experienced by individuals with DS, acting as mediator in this process.

Continuous speech-language stimulation, quality education, participation in everyday problem solving in the family environment and professional training will make a difference in the quest for the autonomy of individuals with DS. Therefore, it is worth mentioning that, in addition to providing job opportunities, it is necessary to prepare these individuals for workplace participation by creating opportunities for stimulation and training, so that they can obtain employment, not merely as part of companies’ efforts to comply with the law, but because these individuals are able to contribute to the same degree as any other citizen.

CONCLUSION

The present study revealed that tutors, sector employees and mothers viewed the communication skills of individuals with DS as “good.” However, these three groups of respondents did not agree on whether the trainees were suited to the workplace. It was also noted that trainees achieved good social interactions in the work environment and that their communication improved after being placed in this environment. The trainees in the present study were not considered “independent”, but changes were observed in their social behavior, including improvements in autonomy and communication. These changes contributed to their empowerment.

Communication and language are critical for placing individuals with DS in the workplace, justifying the role of speech-language therapists in the professional rehabilitation of these individuals. Employment of these individuals leads to improvements in communication performance, demonstrating a continuity of the rehabilitation process both before and during employment and the results brought about by their inclusion in the workplace.

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REFERENCES


Author contributions

TMMFB participated in designing the research project, and in the data collection, data analysis, and writing of the manuscript; ILBL participated in the data analysis and writing of the manuscript; GASA participated in the review of the manuscript; and ICD guided the development of all stages of the study.