Functional activity and communication-social ability of youths with developmental disabilities: a qualitative study

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Abstract. [Purpose] To describe the functional activity and the communication-social ability levels of youths with developmental disabilities and to determine whether demographic factors predict these levels. [Participants and Methods] A mixed, observational and qualitative, study in which parents of students with developmental disabilities were interviewed based on the WeeFIM questions. Both quantitative and qualitative data were analysed. [Results] Data were collected for 30 youths with mild to severe developmental disabilities with mean age 18.5 ± 2.7 years (19 males). Mean WeeFIM total score was 106.2 ± 10.9, indicating relatively high functional and communication-social ability. No significant difference was observed for the total WeeFIM score between males and females and between adolescents and young adults with developmental disabilities. Main themes emerged from the interviews were: Difficulties with smooth and stable walking, transfers to/from bathtub and stairs. Also, youths are expressing a need for independence in self-care, while relationships with their peers are difficult and problems are primarily solved with help from their parents. [Conclusion] Despite the high functional and communication-social ability levels of a group of youths with developmental disabilities, parents revealed that youths had certain difficulties. Therapy should address such difficulties to promote independence and participation of these young people in the community.

Key words: Developmental disabilities, WeeFIM

INTRODUCTION

Developmental disabilities result from lesions on the developing nervous system, and manifest various limitations in function in one or more domains, including cognition, motor ability, vision, hearing/speech, and behavior1). People with developmental disabilities often have impairments in muscle tone and/or muscle weakness and uncoordinated movement, resulting in decreased stability and balance, and decreased ability to perform daily functional activities2–4). They also typically have other impairments, such as sensory or cognitive impairments and problems in social relationships, that are related to their ability to carry out daily functional activities5–7).

Limitations of functional activities and/or decreased communication/socialization levels observed in young people with developmental disabilities often results in a decreased involvement in society (participation), quality of life, and dependence on others8–11). Therefore, it is of great importance to explore the levels of daily functional activities as well as the communication and social ability levels of people with developmental disabilities. This information can guide therapists to plan and implement appropriate treatments in order to improve their patients’ functional activities levels as well as their communication and social ability levels.
The functional activities and communication/social ability of people with developmental disabilities have been investigated in several studies, with most studies exploring these in children or adults with developmental disabilities. However, no study has investigated the levels of daily functional activities, such as grooming, bathing, etc., of adolescents and young adults with developmental disabilities. Further, there is no study regarding the daily functional activities and communication/social ability of a Greek population with developmental disabilities. Only one study has implemented the Children’s Assessment of Participation and Enjoyment (CAPE) and the Preference for Activities of Children (PAC) in Greek people with disabilities. These instruments are used to assess the individual’s ability to carry out specific leisure and social activities rather than daily functional activities and communication/social behavior. It was a cross-validation study of the aforementioned instruments and not an observational study in people with developmental disabilities. It is, therefore, obvious that there is a need for a study exploring the daily functional activities and communication/social ability of people with developmental disabilities in a Greek setting.

Therefore, this study’s aim was to describe the functional activity and communication-social ability levels of adolescents and young adults with developmental disabilities based on the WeeFIM questions. A further aim was to determine whether demographic factors predict functional activity levels and communication-social ability levels in this group.

PARTICIPANTS AND METHODS

This was a mixed study (observational and qualitative) in which parents of students of the Special Occupational High School of Patras were included as participants. Inclusion criteria required the participants to be parents/caregivers of adolescents and young adults with developmental disabilities aged between 15 and 25 years old who could provide information about the youth’s functional abilities.

The WeeFIM instrument (Uniform Data System for Medical Rehabilitation, Amherst, NY, USA) collected both quantitative and qualitative data. The WeeFIM provides an indication of functional motor and cognitive outcomes in children and young people with disabilities and is modeled on the Functional Independence Measure, which is widely used in rehabilitation settings. The instrument includes 18 items that are divided into six areas: self-care (six items), sphincter control (two items), transfers (three items), locomotion (two items), communication (two items), and social cognition (three items). The motor subscale includes the areas of self-care, sphincter control, transfers, and locomotion, while the remaining two areas (communication and social cognition) comprise the cognitive subscale. A 7-level ordinal rating system ranging from 7 (complete independence) to 1 (total assistance) is used. The minimum possible total rating is 18 (total dependence in all activities); the maximum possible rating is 126 (complete independence in all activities). The WeeFIM instrument can be easily administered in 20 minutes or less through direct observation and/or interview, and does not require special equipment. The English version of the WeeFIM, used in the current study, has demonstrated a sufficient amount of validity, reliability, and responsiveness in assessing the functional activities of children with developmental disabilities.

One of the researchers conducted the interviews via telephone calls due to restrictions of face-to-face contact because of the COVID-19 pandemic. The parents did not know the investigator before the time of the interview. In cases in which neither parent was available, the interview was administered to a caregiver familiar with the youth’s functional abilities. Data were collected anonymously and the researcher prepared a text with accounts of the parents’/caregivers’ responses. Interview questions were based on the WeeFIM questionnaire and parents/caregivers had to answer and elaborate on each WeeFIM question (item). Two of the researchers (RL, FN), based on the parent’s answers, scored the WeeFIM items for youth with developmental disability. Total scores for each WeeFIM subscale, as well as a total WeeFIM score, were calculated. The two researchers received training in the WeeFIM questionnaire by a pediatric physiotherapist and researcher with 20 years of experience. All parents provided written, informed consent. The ethical committee of the Department of Physical Therapy, University of Patras (31/06-11-2020) approved the study.

Initially, results were described as means and standard deviations of the total WeeFIM score and WeeFIM subscales score. Following, independent t-tests were used to examine whether there were differences between adolescents and young adults with developmental disabilities of different genders (male, female) and ages (≤18 years and ≥19 years). Data analysis was performed with SPSS.25 (IBM SPSS Statistics for Windows, 2015, IBM Corp., Armonk, NY, USA).

The text with the parents’/caregivers’ accounts were also qualitatively analyzed. Three of the researchers (TB, LR, FN) independently read the text several times and coded the text manually in categories with words describing the meaning of each category. Following, the three researchers met and compared their codes and discussed any disagreements, reaching an agreement on the themes. Independent coding and peer synthesis guards against bias and increases the reliability of the findings. Similar codes were grouped together to come up with the main themes.

RESULTS

Data were collected for 30 participants with a mean age of 18.5 ± 2.7 years (19 males, 11 females) who were special needs high school students. The majority of participants were diagnosed with autism (n=22), while the rest were diagnosed with Down syndrome (n=4), cerebral palsy (n=2), cranial lesion (n=1), and phenylketonuria (n=1). All participants were walking independently. Also, all of them had an intellectual impairment as measured with the Wechsler Intelligence Scale.
for Children, with most of them having mild (n=14) or moderate intellectual impairment (n=13), while very few had severe intellectual impairment (n=3).Twenty-five mothers, three fathers, one grandmother, and one uncle provided data regarding the youths. These adults were 35–50 years old, with the majority of them having a high school education (90%), while the rest had an university education (10%).

The mean WeeFIM total score was 106.2 ± 10.9, indicating relatively high functional and communication-social ability. Males had a mean WeeFIM total score of 106.9 ± 10.5, while females had a mean score of 105 ± 12.1. Adolescents with developmental disabilities (≤18 years old) had a mean WeeFIM total score of 106.4 ± 10.7, while young adults with developmental disabilities (≥19 years old) had a mean score of 105.8 ± 11.6. The results did not demonstrate a significant difference for the total WeeFIM score between males and females [mean difference: 1.89 (Confidence Interval: −7.3 to 11.06)], and between adolescents and young adults with developmental disabilities [mean difference: 0.61 (CI: −7.9 to 9.1)]. Similarly, no significant differences were observed between males and females and between adolescents and young adults for each WeeFIM subscale (Table 1).

Main themes emerging from interviews: The following main themes emerged from the parents’ interviews:

**Theme: Difficulties in gross motor function.** Most youths with developmental disabilities walked independently: According to their parents’ reports, most of the participants who were attending the special high school could walk independently without the use of an aid (walking stick) or wheelchair. Despite walking independently, they may have had difficulties in walking smoothly and quickly or with stability. As the mother of an 18 year-old boy with autism described, “He tires easily and, therefore, he is somewhat slow”. Meanwhile, the mother of an 18 year-old girl with cranio-cerebral injury said, “She

| Youth with DD Sequence number | Age (years) | Gender | Diagnosis | Self-care subscale scores | Transfers subscale scores | Communication/Social cognition subscale scores | Total WeeFIM scores |
|------------------------------|------------|--------|-----------|--------------------------|--------------------------|---------------------------------------------|--------------------|
| 1                            | 18         | Male   | ASD       | 45                       | 34                       | 28                                          | 107                |
| 2                            | 18         | Male   | ASD       | 41                       | 33                       | 30                                          | 104                |
| 3                            | 15         | Male   | ASD       | 48                       | 32                       | 24                                          | 104                |
| 4                            | 16         | Male   | ASD       | 56                       | 35                       | 30                                          | 121                |
| 5                            | 19         | Male   | ASD       | 55                       | 35                       | 28                                          | 118                |
| 6                            | 20         | Female | Down syndrome | 52                      | 33                       | 32                                          | 117                |
| 7                            | 18         | Male   | Phenylketonuria | 35                      | 27                       | 30                                          | 92                 |
| 8                            | 17.5       | Female | ASD       | 51                       | 35                       | 29                                          | 115                |
| 9                            | 14         | Male   | ASD       | 52                       | 35                       | 28                                          | 115                |
| 10                           | 18         | Female | ASD       | 53                       | 35                       | 30                                          | 118                |
| 11                           | 15         | Male   | ASD       | 46                       | 31                       | 32                                          | 109                |
| 12                           | 16         | Male   | ASD       | 40                       | 34                       | 24                                          | 98                 |
| 13                           | 17         | Male   | ASD       | 55                       | 35                       | 34                                          | 124                |
| 14                           | 17         | Female | Down syndrome | 38                      | 28                       | 25                                          | 91                 |
| 15                           | 16         | Male   | ASD       | 55                       | 35                       | 32                                          | 122                |
| 16                           | 19         | Female | ASD       | 46                       | 25                       | 31                                          | 102                |
| 17                           | 24         | Male   | ASD       | 51                       | 35                       | 30                                          | 116                |
| 18                           | 18         | Female | ASD       | 41                       | 31                       | 27                                          | 99                 |
| 19                           | 23         | Male   | ASD       | 45                       | 32                       | 28                                          | 105                |
| 20                           | 19         | Female | Cerebral palsy | 42                      | 26                       | 26                                          | 94                 |
| 21                           | 20         | Male   | ASD       | 46                       | 32                       | 25                                          | 103                |
| 22                           | 18         | Female | Brain injury | 40                      | 27                       | 31                                          | 98                 |
| 23                           | 21         | Female | Down syndrome | 37                      | 26                       | 24                                          | 87                 |
| 24                           | 24         | Male   | Cerebral palsy | 37                      | 29                       | 35                                          | 101                |
| 25                           | 15         | Male   | ASD       | 46                       | 31                       | 21                                          | 98                 |
| 26                           | 17         | Female | ASD       | 50                       | 35                       | 28                                          | 113                |
| 27                           | 16         | Female | ASD       | 55                       | 35                       | 31                                          | 121                |
| 28                           | 21         | Male   | ASD       | 50                       | 35                       | 27                                          | 112                |
| 29                           | 18         | Male   | ASD       | 43                       | 26                       | 22                                          | 91                 |
| 30                           | 24         | Male   | ASD       | 41                       | 27                       | 23                                          | 91                 |

**ASD:** Autism Spectrum Disorder.
walks independently, but she limps”. Further, parents reported deformities in posture during walking; for example, the mother of a 17 year-old girl with autism said, “She walks independently but she humps her back”.

Need for help and/or supervision during transfer to/from bathtub: About half of the parents reported that that youths had trouble getting in/out of the bathtub due to their lack of balance, and that they needed to hold on to a person or a rail to complete this activity. Characteristically, the mother of a 15 year-old boy with autism said, “He needs help to get in and out of the washhtub and he wants to sit on a stool to feel safe that he will not slip in the washtub”. Another mother also said, “He goes to the bathroom by himself, but he needs help to get in and out of the washtub”.

Difficulties in ascending/descending stairs: About half of the parents reported that their child had difficulties when ascending and descending stairs. The majority of them needed to hold onto a rail to feel safe. In particular, the mother of an 18 year-old boy with autism said, “He tires easily on the stairs and, therefore, he always needs to hold onto something to feel safe”. Another mother referenced her 15 year-old boy, saying, “He is floppy when moving and always needs to hold onto the rail or a person to feel safe”. The mother of a girl with Down syndrome also reported her child having balance problems, claiming, “She may lose her balance because she is overweight”.

Theme: Fine motor activities. Difficulties with fine motor skills: A relatively high number of youths with developmental disabilities had insufficient fine motor skills. Most parents reported that their children experienced difficulties during eating. Particularly, although the youths were eating/drinking independently when using a spoon and fork, they had difficulty when using a knife. The mother of a boy with autism pointed out, “He eats by himself, but he doesn’t use a knife; he prefers drinking from a plastic glass” Youths with developmental disabilities also had difficulties with tying their shoelaces and buttoning up, the main problems they faced when dressing. Otherwise, almost all of them were dressing themselves. Rarely, other problems were affecting dressing competence. A mother reported that her 19 year-old daughter with autism “needs help with dressing because she has a movement problem due to marked kyphosis”.

Expressing a need for independence in self-care: Youths with developmental disabilities were expressing a need for independence in certain activities by refusing to accept instructions from others. In her interview, the mother of a 20 year-old woman with Down syndrome mentioned that her daughter wanted to do all of her grooming herself (brushing her hair, dressing, handwashing, etc.) However, the same mother added that her daughter required supervision and help in order to correctly complete these activities. Furthermore, the mother of an adolescent with autism said, “When he was 6 years old, he started washing himself; however, even now he is in a hurry and does everything clumsily and not within the required time”. The same mother added, “He doesn’t want us to show him to do it properly”.

Theme: Cyst and bowel control: The majority of youths with developmental disabilities had excellent cyst and bowel control. However, the parents of three girls with Down syndrome mentioned that their girls had difficulties controlling cyst sometimes as they forget and do not make it until to go to the toilet.

Theme: Social interactions and communication−Relationships with peers are difficult: More than half of the participants had problems in their social relationships with peers. These youths, however, had good relationships with adults, and especially, adults who they knew for some time, such as their therapists. The mother of a 15 year-old boy with autism said, “He is close to his siblings, but can’t communicate and make friendships with his peers and adults he doesn’t know”. The same mother mentioned, “He is annoyed when touched by someone unfamiliar to him”. Different reasons for difficulties in making close relationships with others were reported for a youth with a different diagnosis such as issues in bodily appearance. In particular, a mother mentioned that her daughter with craniocerebral injury “has some body marks due to injuries and she avoids her peers because she is ashamed”. Nevertheless, some of the youths in the current study were very sociable with their peers. For example, the father of a girl with Down syndrome said, “She is very sociable. The first time she meets someone, she considers him/her a friend”, and added, “She can’t do without friends”.

Problems are primarily solved with help from parents: Almost all of the participants received help from their parents, especially their mother, in handling everyday concerns and problems. This indicates the important role that family involvement plays in all aspects of the participants’ lives. Despite this, the mother of a 17 year-old girl with autism reported that “she prefers to discuss all of her daily concerns with the psychologist who is treating her since she was very young, rather than me”.

Difficulties with communication and memory: Most of the participants had communication problems, most often in how to verbally express themselves. Regarding speech comprehension, several parents reported difficulties in their child’s understanding of more profound meanings. The mother of a 16 year-old boy said, “Despite the fact that he can understand well, he has difficulty understanding something told to him or that he hears on TV that has a deeper meaning”. The same mother mentioned that her son “has a problem when expressing himself verbally or written” and she continued, “However, this is not a limitation to his social relationships as he is pretty talkative, cooperative, and warm-hearted”. Furthermore, most of the parents reported that their children were forgetting to carry out daily activities (e.g., grooming, homework), and needed a reminder to some or parts of these activities. The mother of a boy with cerebral palsy said, “He is fine, but he needs someone to remind him to wash his hands”, while another mother said that her son with autism “washes himself during bathing, but forgets to wash his hair or other parts of his body”. Youths’ mood also affected the carrying out of daily activities, and as the mother of a boy with autism said, “It depends on his mood; when he is upset, he doesn’t want to do anything”.

J. Phys. Ther. Sci. Vol. 34, No. 11, 2022
DISCUSSION

In this study, quite high functional activity and communication-social ability levels were observed in youths with mild to severe developmental disabilities, probably because most of the youths had mild to moderate disabilities. Despite this, their parents’ insights revealed that they had difficulties smoothly or completely performing certain functional and communication activities.

Regarding gross motor abilities, difficulties were primarily reported for transfers, such as transferring to/from the bathtub and climbing/descending stairs. There is no known study that compares findings for these specific activities, but a previous study reviewed difficulties that middle-aged participants with intellectual disabilities had with activities like doing household tasks or laundry. Movement abnormalities, such as lack of coordination, atypical posture, sensory processing, and voluntary movement speed have been reported as contributing to difficulties with functional activities in young people with autism or other developmental disabilities. Further, difficulties with some fine motor skills (e.g., using a knife, buttoning) that were observed in the current study’s participants may be explained by a weak maximum grip strength often observed in this cohort. Grip strength has been found to have an impact on adaptive daily living skills from childhood through middle adulthood in people with developmental disabilities.

Although the youths of the current study expressed a need for independence when performing self-care activities (i.e., bathing, grooming), they still required guidance or help to complete them. Difficulties in independently performing similar activities (i.e., washing, bathing, or grooming) were also reported in a previous study which included middle aged adults with intellectual disabilities. As parents also reported in the current study, youths with developmental disabilities needed a reminder to complete parts of these activities. This may be because they could not fully understand the requirements of such activities as most of them also had an intellectual disability. Furthermore, low muscle tone characterized in people with Down syndrome can result in a flaccid cyst sphincter and may be the reason that three young girls in the current study with Down syndrome still had some problems with fully controlling their cyst.

In agreement with the current study’s results, previous studies have also found that youth with developmental disabilities find it hard to make friends because of their disabilities. Some reasons for these difficulties, often include issues with access to public transportation, the cost of funding staff to accompany them on social outings, and having minimal finances and/or little control over them. Fulford and Cobigo also pointed out that people with intellectual disabilities tended to be friends with others with intellectual disabilities, and it was difficult to have friends who did not have disabilities. Further, living independently has been associated with having a greater ability to see friends and girlfriends/boyfriends, which was not the case with the current study’s participants as all of them were living with their parents.

In line with our findings, people with developmental disabilities also demonstrated low levels of self-determination in previous studies. Although cognitive ability can impact self-determination, other factors also contribute to low levels of self-determination. Such reasons are more directive relationships with their parents/caregivers and restrictive environments, which results in fewer opportunities for people with developmental disabilities to develop self-determination skills, such as decision-making and goal-setting. Families often have difficulties promoting self-determination and independence, likely because they feel their members with developmental disabilities are not mature enough and, therefore, they have concerns for their safety. Accordingly, a practitioner’s role should be to make families understand how crucial it is to promote self-determination for their family members with disabilities, especially as they transition to adulthood, i.e., transition in adult healthcare, tertiary education, pursuing vocational opportunities, or even moving out of the parental home. This should be central to the practitioners’ aims for people with disabilities as they transition to adulthood in order to support meaningful community engagement, by taking into account not only the families’ perspectives (goals, desires, decision-making), but also the youths’ perspectives. It is important that practitioners recognize that youths with developmental disabilities should express their views about their own lives, as well as the programs and policies that affect their community engagement and transition to adulthood.

A strength of the current study is that it provides a comprehensive understanding of the ability of youths with developmental disabilities to perform daily functional activities, considering that there is a lack of such a study in literature. Another strength is that three researchers coded the transcripts independently and then developed themes through subsequent discussion. A limitation is the fact that interviews were not tape-recorded, but were conducted via phone calls and, although the reviewer wrote down most of the parents’ narrations, few details may have been missed. Also, almost all of the youths were diagnosed with autism disorder and mild to moderate intellectual disabilities, so this study’s findings can probably only be generalized to youths with autism and with mild to moderate intellectual disabilities. Families of youths with developmental disabilities were also of traditional structure (dual heterosexual parental homes), and parents received only secondary education. Thus, future research could focus on more diverse families (e.g., in terms of education, socioeconomic class, etc.) in order to provide a more complete understanding of how these components could best affect the youths’ levels of functional activities and social ability. The relationships among themes identified in this study could also be further explored in future research since this information may offer insights to therapists about how to help improve youths with developmental disabilities’ levels of functional activities and social ability.
In conclusion, this study observed relatively high functional activity and communication and social ability levels in youths with mild to severe developmental disabilities. Parental insights revealed that the participants had difficulties with completely or smoothly performing some functional and communication activities. These findings suggest that therapists should focus on areas where these youth receive appropriate treatments in order to promote independence and participation in the community.

Funding and Conflicts of interest
The authors declare no conflicts of interest.

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