Transition Planning in adolescents with Low Functioning Autism

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Key Words:
Transition Assessment, Vocational Skills, Adolescents, Low Functioning Autism

Abstract

Aims & Objectives:
1) To assess transition and vocational skills in adolescents with Low Functioning Autism.
2) To evaluate the understanding and expectations of parents and educators regarding the transition.

Methodology: A cross sectional descriptive study. 14 children (Age range 12 to 18) with low functioning autism were assessed using Behavior Problem Inventory(BPI), Transitional and Vocational Skill Assessment Scale(TVSAS), Environmental Job Assessment Measure(E-JAM). Parents and Teachers were interviewed using Semi structured interview, The Parent Transition Inventory (PTI), Self Determination Scale (SDS)–Parent form and Educator Form.

Results: Self stimulatory behaviors (frequency 41.21%, severity 16.09%) were higher than self injurious and aggressive behaviors. Level of independence was in descending order (moderate to min) in following skills -Self Help, ADL, Vocational, Community integration, Time and money management, Safety, transport and sexual awareness. Maximum supports required for vocational participation were identified in areas of work behaviors and social interaction. Qualitative analysis of data collected from parents and teachers showed their expectations for supported employment in future.

Conclusion: Transition Assessment identified the level of transition readiness. It helped to create a profile including the supports required for success in vocational participation and this helped in transition planning.

Introduction

Autism Spectrum Disorders (ASD) are lifelong disabilities (APA, 2000), and adolescence can be a time of increasing challenges for individuals with an ASD and their families. Functional limitations caused by ASD continue into adulthood and often create barriers to independent living and stable long-term employment (ASA, 2008). Levy et al (2012) in their review mention that amongst the factors that predict occupational and employment outcomes, the most consistent correlate is IQ. Individuals who have ASD and comorbid intellectual disability (ID) reflect less than optimal functioning and independence. The job opportunities and employability also are lesser in the low functioning autism as they have greater behavioral challenges and co morbidities. In spite of these barriers it is seen that they display trainability: they are able to master some skills if taught to them consistently and with required supports. Studies show that there exists a need to better understand the factors that are related to effective and efficient transition to adulthood in young people with ASD. Taylor et al in their study suggest that a transition plan should be all-inclusive, addressing a compendium of domains: current levels of behavior, postsecondary education and employment, recreational/leisure/physical activities, transportation, social skill enhancement, communication, sexual expression etc.

Rationale of this study is to understand the transition issues in low functioning adolescents with autism from occupational therapy perspective. It is expected that a rigorous transition and vocational skill evaluation will help in transition planning which in turn will produce more predictable adult outcomes for adolescents with ASD. Families and educators are critical members of the transition team. A transition plan must include a process for ensuring success of the plan over time by responsible personnel. Therefore study also tries to get an insight into the parents and educators understanding and expectations about transition.

Aims & Objectives of this study are:
(1) To conduct a transitional assessment to understand the present transition and vocational skill status in adolescents with Low Functioning Autism
(2) To study the present understanding and future expectations of parents and educators of adolescents with Low Functioning Autism regarding the transition.
Methodology

Study Design: A cross sectional descriptive study.

Participants: 14 adolescents (11 boys & 3 girls) with low functioning autism were selected by convenience sampling, from the pre-vocational class of a special school were selected for the study. All 14 students fitted the inclusion criteria of adolescent age range (12 to 18) and having a diagnosis of ASD, IQ range (50 to 70 i.e. trainable range), and therefore were included in the study. 14 Parents (Mothers) and 6 educators of the adolescents were also part of the study. Written Consent was taken for all of them.

Outcome Measures: were Behavior Problem Inventory (BPI), Transitional and Vocational Skill Assessment Scale (TVSAS), Environmental Job Assessment Measure (E-JAM). Parents and Teachers were interviewed using Semi structured interview, The Parent Transition Inventory (PTI), Self Determination Scale (SDS) – Parent form and Educator Form.

Procedure: 14 children were observed for 6 weeks, 5 times a week for an hour everyday in the prevocational class of the special school. They were evaluated and were scored using Behavior Problem Inventory (BPI), Transition and Vocational Skills Assessment Scale (TVSAS), Environmental – Job Assessment Measure (E-JAM). The scoring was done based on the observations as well as the inputs from their parents and special educators. The parents and teachers were also interviewed using semi structured interview, Parents transition inventory (PTI), Self determination scale (SDS) during the six week period.

Data Analysis: The data collected using BPI, TVSAS and E-JAM is quantitatively and descriptively analyzed. The data collected from the parents and teachers interview, PTI and SDS was qualitatively analyzed and themes were developed from the same.

Results

Graph 1: % Severity and % frequency of Self injurious behaviors (SIB), Self stimulating behaviors (SB), Aggressive/ destructive behaviors using Behavior Problem Inventory.

Graph 2: % Level of independence in various transition skills as per transition and vocational skills assessment scale (TVSAS).
Graph 3: % Vocational Demands and % Supports required for successful vocational participation as per Environmental and Job Assessment Measure (E-JAM).

1. The severity and frequency of Self-injurious behaviors (SIB), Self-stimulatory behaviors (SB), and Aggressive / Destructive behaviors (A/DB) was measured using behavior problem inventory. It is seen that the %SB scores are greater than the %SIB and %A/DB scores.

2. The level of independence in transition skills as measured using TYSAS shows that Moderate to Minimum independence (i.e., independence with assistance) is seen in the following areas in descending order—Basic Requisite Skills (60.02%), Self Help Skills (59.41%), Activities of Daily Living (48.04%), Play & Leisure Activities (45.30%), Language & Communication (43.11%), Vocational Skills (40.78%), Community integration (33.10%), Time and money management (20.50%), Safety, transport and sexual awareness (20.34%). That is requirement of supports will be required for success in the above skills.

3. Environmental Job Assessment Measure (E-JAM)
   (a) Demands in the following areas were Work Behaviors (55.40%), Physical (40.20%), Environmental (42.50%), Skills (35.04%), Social Interaction (40.40%).
   (b) Supports required in the following areas were Work Behaviors (56%), Physical (44%), Environmental (34%), Skills (50%), Social Interaction (79%).

4. Qualitative analysis of data collected from parents and teachers led to development of two themes – i.e. present state, future expectations. These were further divided into further categories and subcategories.

Discussion

Theme 1: PRESENT STATE

(a) Challenging Behaviors

Perhaps the greatest challenge to those who interact with individuals across the autism spectrum is the presence of challenging behaviors. The risk of behavioral deterioration in adolescence or early adulthood is highest in individuals who have lower IQ.

(Graph 1) In the current study it was found that the % severity and frequency of Self-stimulating behaviors were greater than Self Injurious behaviors and Aggressive behaviors as rated by parents and teachers.

"It's becoming increasingly difficult to control his behaviors. It was easier when he was younger."

Parents mentioned that many a times they are successful in coaxing or threatening their sons and daughters into “behaving”. But there are times when they are unable to control behaviors of their tall, grown up, obese children as they themselves are aging like their children. Kobayashi et al mentioned that even if the frequency of the difficult behavior decreased in adolescence, the results of such behavior on the part of individuals who were taller, heavier and stronger were more distressing or dangerous than the same behavior in children.

"He often doesn't sleep till wee hours in the mornings....sometimes he doesn't sleep at all....the next days to such sleep disturbances are horrible....he goes haywire."

IJOT : Vol. 47 : No. 3 69 September 2015 - December 2015
When asked about the causes of these behavior exacerbations, parents gave many causes one of it being sleep disturbances as mentioned in the above verbatim. This finding in line with Cohen et al’s study in which they state that the consequence of disrupted sleep in individuals with ASD is potentially dangerous and that it exacerbates repetitive behaviors, and other maladaptive behaviors (e.g. self injury, tantrums and aggression) during daytime. The therapist suggested a regularized sleep routine to avoid these behavioral exacerbations. For eg, one participant had disturbed sleep since a few days as stated by mother, after a thorough analysis it was found that his obsession with watching videos just before sleep caused this, and so a discontinuation of the same was suggested.

“It’s very embarrassing in public”

Parents mentioned the display of sexual behaviors like touching their genitals in public as a major concern. Parents mentioned that adolescent stage brings a lot of changes physically and emotionally and this causes a lot of stress not only to their children but also to them as parents. Some of the parents mentioned that they have been training their children, that these behaviors are private and should not be done in public. Mothers of female children have also taught them the routine during menstrual periods with some success.

“Most of the time I just give up….and let him have his way”

Parents said that the easiest way to deal with challenging behaviors may be to give up and/or give in. But they also confessed that though this approach appears to resolve the immediate situation, it does not teach their children right behaviors.

“Prevention is better than Cure”

Parents and educators mentioned that knowing the behaviors well, they try to avoid the occurrence of a major behavioral outburst, though this is not practically possible all the time. The therapist introduced parents to the basics of functional behavioral analysis so that they can analyze the behaviors and their functions in detail and provide behavioral supports accordingly. Some behavior management strategies suggested to the parents were allowing breaks for self-regulation, offering choices, and deal with difficult behaviors through supportive problem-solving when the child is no longer upset. Visual Schedule was suggested to all participants for their daily schedule, as knowing “what next” will help in avoiding stress and anxiety and would prevent exacerbation of maladaptive behaviors throughout the day.

(b) Performance Areas/ Skills

As per the data collected using Transition and Vocational Skills Assessment Scale the moderate to minimum independence (i.e. independence with assistance) was seen in following skills in descending order -Self Help, ADL, Vocational, Community integration, Time and money management Safety, transport and sexual awareness (Graph 2)

Self Help and ADL/Skills is the area which showed highest scores. This finding is in line with the study by Duncan et al in their study have mentioned that despite the fact that children and adolescents with ASD have poorer Daily Living Skills (DLS) than children with other developmental disorders or typically developing children they exhibit a relative adaptive behavior strength in the area of Daily Living Skills (DLS). Better DLS may facilitate a positive adult outcome is very promising because unlike many other skills that are lacking in individuals with ASD, DLS is concrete and may therefore be more amenable to intervention. Furthermore, many DLS that are critical to success in the adult world do not rely as heavily as other adaptive behavior skills on the social-communication abilities impaired in individuals with ASD.

Vocational Skills showed lesser scores than ADL. These participants have been working in the prevocational class since a year now. They do simple assembly tasks under supervision of educators.

“This anklet I am wearing, is made by my son …..so proud of him”

Almost all individuals with ASD have skills and talents that can be developed to allow them to maintain meaningful employment. Often a person with ASD will develop an area of strong interest that to others seems unusual in either the topic or intensity. Reframing these areas of interest from “obsessions” or “narrow fields of interest” into “passions”. It can be a unique role the unique role of occupational therapists to be able to identify these abilities and match them with the opportunities and supports necessary to achieve employment. Graph 3 shows the % performance & the supports required in the areas of work behaviors, physical, environmental, skills and social interaction. Occupational therapists can play a role in careful consideration and arrangement of necessary supports and accommodation leading to success of the work experience. In the current study some suggestions of supports made improve work behaviors were simplification of tasks, prompts and redirection to complete the tasks, uncluttered environment, noise control, frequent breaks, prompts for interaction.

Language, Communication & Social Skills all of the participants were non verbal, they would interact only when approached, will express basic needs like food, water, toilet through gestures. Their receptive language was fair they could follow simple one to two step instructions. A few of participants were suggested to use android application which will be easy to use and economical and at the same time will help the individuals to make choices and communicate needs. Thus capitalizing on their visual spatial skills.

Play & Leisure Activities & Time management: Parents mentioned that most of the participants are good physically and can be good in physical sports. Some are good at music some at crafts. These potentials have to be identified and channelized. But most of them spend time in TV, videos etc and waste time which again leads to problem behaviors. Previous research examining the time use adolescents with intellectual disabilities indicates that they participate more frequently in solitary activities. They do not engage in social activities, energy-consuming activities, and activities that are structured or require.
preplanning such as organized sports, music lessons or youth groups. Occupational therapist can play a major role in play & leisure activities in exploration as well as performance.

Theme 2: Future Expectations

(a) Fear of the future

"I spend many sleepless nights thinking about my daughters future"

Parents mentioned about the fears they have regarding their children’s future. During their child's adolescence, parents are often anxious about their child's independence and future. Parents of adolescents with ASD report stress levels beyond even the high levels of depression and anxiety. (White & Hastings, 2004). Parents also talked about strong bonds with other parents who understand can understand their condition and support them. These emotions need to be identified and appropriate counseling and psychosocial upliftment can be provided by an occupational therapist or else these emotions can affect the transition planning process.

(b) Transition Planning

When asked about what were their expectations for their child’s future most of them hoped for a part time supported employment but stated that they hadn't thought about their children’s children’s future living options, guardianships, financial supports though they considered to be major concerns. Occupational therapist provide an insight to the parents and educators, into the present level of transition readiness of the participants using the results of transition assessment and thus provide a push for the parents and educators to get ready for whole new phase in their children’s lives. Occupational Therapy can play a role in advocacy i.e. providing parents and educators with information regarding various resources that will help them in transition.

"It was an eye opener...really"

Many of the parents stated that through their participation in this study they got a direction for transition planning of their children into adulthood.

(a) Fostering independence

As parents and educators were interviewed as per the self determination scale, to identify whether participants have the capabilities and opportunities to function independently. It was found that the participants were able to understand their capabilities and interests to some extent in the pre vocational class. It was observed that participants could perform the assembly tasks in the prevocational class only with educators prompts and support. It was observed that in some of the participants it was a learnt dependence as enough opportunities seemed to be not present, to foster better independent vocational skills. An individual work system was suggested to the participants to foster as much independence as would be feasible considering they are low functioning adolescents. A work system will help the participant to understand what he is supposed to do, how much work he is supposed to do, it also teaches the finish concept. This shall foster better on task behaviors as visually presented sequence of activities, makes the task more predictable, and organized.

Conclusion

The transitional assessment of the participants identified the present level of the participants in various occupational performance areas ADL skills, Vocational Skills, Play & Leisure skills, Language and communication skills etc. Qualitative analysis of data collected from parents and teachers showed the participants present status as well as their future expectations regarding transition. This descriptive study through its quantitative and qualitative evaluations helped in laying a stepping stone for transition planning for the participants with low functioning autism as well as their parents and educators. An insight into various supports that might be required for successful transition and vocational participation was gained and the role of occupational therapy in transition assessment and planning was emphasized.

Aknowlegements

1. I would like to thank the Almighty God and my parents.
2. I would like to thank Mrs. Paromita Majumdar, Principal, Sunshine School, Vashi.
3. I would like to thank all my participants, their parents and educators for their cooperation.

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