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Skill acquisition and task responsibility in children with autism: an item level analysis of the PEDI-CAT

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BOSTON UNIVERSITY
SARGENT COLLEGE OF HEALTH AND REHABILITATION SCIENCES

Thesis

**SKILL ACQUISITION AND TASK RESPONSIBILITY
IN CHILDREN WITH AUTISM:
AN ITEM LEVEL ANALYSIS OF THE PEDI-CAT**

by

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B.S. Boston University, 2012

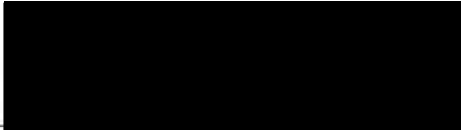
Submitted in partial fulfillment of the
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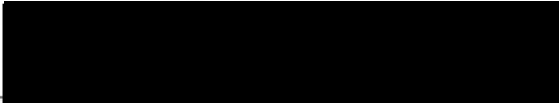
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ABSTRACT

Objective: This study examined differences in the age when the performance of a daily activity is considered easy for a child and the age when the child can take on most responsibility for the corresponding task. A sample of children with autism was compared to a normative sample. **Methods:** This was a secondary analysis of PEDI-CAT data from an autism sample (n=356) and a normative sample (n=2,205). Children (ages 3-21) were classified into one of six age groups. Crosstabs were conducted to determine the age group when 50% of parents in each sample reported that a Daily Activity item was “easy” and when 50% reported their child took “most responsibility” for a corresponding Responsibility item. Visual analysis examined differences in these two points.

Results: Parents of children and youth with autism reported that the majority of Daily Activities were “easy” at a later age group compared to the normative sample. “Most responsibility” also was reached a later age group in the ASD sample or not reached at all.

Conclusion: For children and youth with and without autism, there is an age gap between when relevant skills are mastered and when they take responsibility for managing the overall task.

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**Skill Acquisition and Task Responsibility
in Children with Autism:
An Item Level Analysis of the PEDI-CAT**

Studies have shown that children with autism spectrum disorders (ASD) have limited functional independence (Brown et al., 2011), and often show low levels of independence in activities of daily living (Whyatt & Craig, 2011; Noterdaeme, Wriedt, & Höhne, 2010; Eaves & Ho, 2008). Parents of children with autism hope that their child will become independent in adulthood, yet previous research suggests that the children and youth with autism do not progress to take on more responsibility for daily life tasks from the parent compared to their peers without ASD (Bilgin & Kucuk, 2010; Kao, Kramer, Liljenquist, Tian, & Coster, 2012). The relation between mastery of relevant activities and ability to take responsibility for the overall task is unclear. The present study used a new measure, the Pediatric Evaluation of Disability Inventory – Computer Adaptive Test for Autism Spectrum Disorders (PEDI-CAT ASD), to examine this question of daily activity in a large sample of individuals with and without autism.

Children with autism frequently are delayed in mastering their activities of daily living (ADL). A cross-sectional study focusing on functional independence found that the majority of children with autism had moderate to low functional independence, regardless of their specific autism spectrum diagnosis – Asperger’s, Autistic Disorder or PDD-NOS (Brown, Ouellette-Kuntz, Hunter, Kelley, Cobigo, Lam, 2011). This finding suggests that there is a factor in autism beyond symptom level that affects level of functioning. Another study found that adolescents and adults with autism followed over a ten-year

span, on average, were performing only one-third of daily living skills independently (Smith, Maenner, & Seltzer, 2012). The lack of independence in ADLs leads to a decreased independence in early adulthood. Previous studies have found that two thirds of individuals with autism were not living independently in adulthood (Billstedt, Gillberg, & Gillberg, 2005). In one longitudinal study of 124 individuals with autism, only 4% had complete independence in their adult lives (Billstedt, Gillberg, & Gillberg, 2005).

In order to be successful in developing the skills necessary for independence in self care tasks, a child must have the necessary physical capacity, problem solving skills, and attention abilities (Metz et al., 2012). Several studies have shown that children with autism have higher rates of motor impairment than persons without autism (Whyatt & Craig, 2011; Noterdaeme, Wriedt, & Hohme, 2010). However, the relation between motor delays in children with autism and functional outcomes has not been studied. It is possible that motor difficulties may contribute to delays in skill acquisition in children with autism.

Difficulties with responsive joint attention, the ability to focus one's attention between another person and an object, may limit the ability to watch others, which is one of the most common ways that children learn the skills needed to function independently (Thurm, Lord, Li-Ching, & Newschaffer, 2007). Gillespie-Lynch and colleagues (2012) found that impairments in responsive joint attention directly affected the acquisition of daily living skills. Difficulties in joint attention affect the child's ability to determine what is expected, i.e. the child may have difficulty shifting his or her attention from the

parent's voice teaching how to use a toothbrush to watching what they are actually supposed to be doing with the toothbrush. When children with autism have unclear representations of what is expected of them, they do not initiate the expected behaviors or perform the expected qualities required of the activity (Hume, Loftin, & Lantz, 2009).

Results from studies relating IQ scores in children with autism found that there is no clear association to functional outcomes. Regardless of IQ, persons with autism rely heavily on others to complete daily living tasks (Hume, Loftin, & Lantz, 2009). In one study over 50% of participants with autism had poor functional outcomes, regardless of IQ (Eaves & Ho, 2008).

Learning a new task is often difficult for children with autism. One theory is that task stimuli may not be motivating enough to initiate task completion (Gillespie-Lynch, Sepeta, Wang, Marshall, Gomez, Sigman, & Hutman, 2012). Individuals with autism display lower levels of social interest and this factor may reduce spontaneity in skill demonstration, thereby requiring adult prompting for task initiation (Charlop, & Haymes, 1994). Lower levels of spontaneous demonstration may, in turn, reduce the amount of practice undertaken when learning a new skill, and thus increase the time it takes to master the skill. Lower social interest may also contribute to a decreased initiative in taking on the responsibility for the task from their caregivers.

Some methods of intervention have been shown to increase a child's independence in ADLs. Single subject design studies have demonstrated that when a child with autism is taught strategies for a specific task, their independence on that task can be increased. Children with autism who were completely dependent on their parents

for ADLs were able to complete the task independently once trained with pictorial self-management (Pierce, & Schreibman, 1994). A review of three focused interventions found that children could increase their independence through Self-Monitoring, Video Modeling, and Individual Work Systems (Hume, Loftin, & Lantz, 2009). In Individual Work Systems, a child is given clear expectations of what is needed to complete a task and, with that clarity, the child is able to complete the task independently (Hume, Plavnick, & Odom, 2012). In the above-mentioned interventions, the children were not taught the individual skills needed to complete the task, but rather strategies of how to complete the task (i.e. attention and initiation).

Children with autism also have impairments in executive functioning and problem solving (Gilotty, 2002). Difficulties in executive functioning may be a contributing factor to lower levels of functioning in children with autism when compared to peers (Hume, Loftin, & Lantz, 2009). Impairments in executive functions in children with autism may limit their ability to take on more complex tasks and thereby take responsibility from their parents. Executive functioning involves planning, sequencing actions in effective order, and flexibility to adapt. Although substantial research on identification, assessment, and treatment of children with autism has been conducted (Eaves, & Ho, 2008), there has been little direct attention focused on why a child with autism shows limited management of task responsibilities when compared to their peers. It is currently unknown if children who have acquired the relevant skills will eventually take full responsibility of the relevant task. If the child does take on responsibility, it is unknown whether that shift in responsibility occurs after a longer period of time compared to peers

without autism.

The newly revised Pediatric Evaluation of Disability Inventory-Computer Adaptive Test (PEDI-CAT) offers a tool to investigate this topic further. The PEDI-CAT is a parent-reported questionnaire developed to measure function in the pediatric population. Recently it has been adapted for use with the autism population (Kramer, Coster, Kao, Snow & Orsmond, 2012). The focused domains of this measure are Mobility, Daily Activities, Social-Cognitive, and Responsibility. The Daily Activities scale has 68 items looking at the areas of eating and mealtime, getting dressed, keeping clean, and home maintenance. The Responsibility scale is a 51-item domain with content focused on tasks involving organization and planning, taking care of daily needs, health management, and staying safe (Haley, Coster, Dumas, Fragala-Pinkham, & Moed, 2012). The design of the PEDI-CAT facilitates analysis of the gap between skill acquisition and task responsibility in children with autism, as it addresses which daily activities the child is completing and whether or not the child has taken any amount of responsibility from his or her parents for managing the larger tasks that require multiple activities to complete.

Further research is important to help clinicians determine whether to focus intervention on development of a specific skill to ensure independence in a child with autism, work with the family to shift task responsibility to the child, or focus on the executive functioning areas that are required to manage daily tasks. This study addressed this need. The specific research questions were:

- How does the age when a daily activity skill is acquired compare to when

the child has most responsibility for the larger task associated with that skill?

- How does the age gap from skill acquisition to task responsibility compare in youth with ASD compared to a normative sample?

Methods

This descriptive study is a secondary analysis of data originally collected to determine the reliability and validity of the PEDI-CAT for a population of children with autism.

Instrumentation

The parent reported PEDI-CAT ASD was used to gather information from the participants with a focus on Daily Activities and Responsibility domains. Items in the PEDI-CAT Daily Activities domain are rated on a four-point Likert scale addressing how difficult a task is for the child to perform: “Unable,” “Hard,” “A little hard,” and “Easy.” The Responsibility rating scale measures the shift of responsibility from parents, to shared responsibility, to the young person taking all responsibility, with a five-point scale.

Procedure

Data were collected nationwide for the sample with ASD via a secure website using a third-party host. To be accepted in the study, the following criteria had to be met: (1) The child had been diagnosed with Autism Spectrum Disorder, including Autism, Asperger’s syndrome, or Pervasive Developmental Disorder-Not Otherwise Specified

(PDD-NOS), (2) The parent and child currently lived in the United States of America, (3) The child was between the ages of 3 years, 0 months and 21 years, 11 months, (4) The respondent was the child's legal guardian (even if the child was above the age of 18). The research team used two additional screening questions to reduce the risk of enrolling respondents purposefully misrepresenting their eligibility for participation, a common risk in internet research (Kramer, Rubin, Coster, Helmuth, et al., in press): (5) What services does your child currently receive? (6) How did you find out about this survey? The final two questions were added to act as a safeguard to eliminate participants who answered with unexpected or illogical responses.

Human ethics approval was received prior to conducting the online survey. Parents completed a demographic questionnaire about their child and their family context and the Social Communication Questionnaire (SCQ)- Current. Parents then answered the full item pools for the Social/ Cognitive (68 items), Daily Activities (76 items), and Responsibility (58) domains of the PEDI-CAT –ASD.

Normative data were collected via the Internet by an online survey company. The company has an online panel ($n = 115,000$) who have regularly participated in online surveys. The survey company contacted only panel members with one or more children under 21 years old and with home addresses within the contiguous United States. These parents were asked to answer a series of screening questions (i.e., was the child receiving early intervention services, or did the child have any limitation in personal care activities, routine needs, play, or recreation) to determine their eligibility and placement in either the normative or a disability sample. The company used a quota sampling method based

on child's age to ensure that sufficient cases were collected within each of the age strata (100 cases for each age year under the age of 21). Within each age group, equal proportions of male and female children were selected. This sample included 2,205 respondents to represent the normative sample. (Haley, Coster, Dumas, Fragala-Pinkham, Kramer, et al., 2011)

ASD data were downloaded from the secure website into SPSS. Duplicate respondents and respondents who did not provide data beyond initial consent were removed from the database. One respondent later determined to not meet inclusion criteria was included in Daily Activities and Responsibility analyses; however, given the large sample size, this error was not expected to impact results.

To gain consensus on which Daily Activities items are associated with which Responsibility items, a survey was distributed among 50 graduate occupational therapy students. Participants were asked to indicate the Daily Activity items that they considered an essential skill needed for a child to complete a specific Responsibility item independently. Items with the highest consistency among raters were used for further analysis.

Participants

The initial data set of individuals with ASD consisted of 365 respondents with 358 responding to the Daily Activities scale and 353 to the Responsibility scale of the PEDI-CAT (Tables 1 & 2). The children ranged in age from 3-21, with an average of 11.9 years (SD = 4.67). Most (83.3%) of the children in the sample were male; 52% were diagnosed with autism; 25.5% with Asperger's disorder; 22.2% with PDD-NOS; and

0.3% unknown. By parent report: 54.7% of the sample had average to above average IQ, 19.5% had borderline IQ, and 25.9% had somewhat to significantly low IQ scores, while 21.9% of respondents reported their child had an intellectual disability.

Data Analysis

Age groups were created to help reduce the variability often found within the autism population. Ages were clustered into six separate groups, with three ages in each group based on cognitive levels and common transition points (e.g., school transition) (Table 3).

Analyses were conducted via SPSS software to identify the age group when a Daily Activity item was first rated “easy” by more than 50% of respondents in the ASD sample, and when more than 50% of the children were reported to take on “most” responsibility. This analysis was repeated for the normative sample. An exploratory descriptive analysis was conducted to identify patterns in the responsibility domain. Daily Activity and Responsibility items that were specific to physical maturation, one gender or legal requirements (e.g. “voting in local and national elections”) were removed from analysis. The differences in age for Daily Activity mastery and assumption of most Responsibility were compared between the normative and autism sample via visual analysis using a bar graph.

Results

Daily Activities

There was no difference between the ASD and the normative groups in age of skill mastery on 13 of the daily activity items (Table 4). Eleven of these items were

reported “easy” for both populations in the youngest age group. For 22 Daily Activity items, there was one age group difference in when the item was reported “easy”, with the ASD group showing a delay (Table 5). For 21 Daily Activity items, there was a delay of 2 age groups for the ASD sample, and three Daily Activity items had a delay of three age groups (Table 6). Eight Daily Activity items were never reported “easy” for at least 50% of the ASD sample (Table 7). Many of the items never reported “easy” were related to fine motor activities, i.e. fastens a necklace or a chain.

Responsibility

Table 8 lists the 37 Responsibility items where 50% of the ASD sample never achieved having most of the responsibility for that task. If the normative sample did not reach “most responsibility” on an item until age group 4 (12-14 years) then the ASD sample never reached “most” or “full responsibility”. When the normative sample reached responsibility at a younger age (<group 4), the ASD sample was reported to take “most responsibility” but often did not reach “full responsibility”. There were three exceptions to this pattern: “Keeping electronic devices working”, “coping with stress/worry/anger” and “packing items for an overnight stay”, as the ASD sample never reached having “most responsibility” for these items, even though the normative sample reached this level before age group 4.

Daily Activity Items with Responsibility Items

Figures 1-9 display when the sample reported “most responsibility” for the Responsibility tasks and aligns these items with the associated Daily Activity reported “easy”. These figures display the results from both samples showing the age groups when

the sample can complete an activity easily and when they can manage the overall responsibility task that utilizes those activities. There were no Daily Activity items that were clearly associated with two items: “Having items needed for day,” and “Staying safe in familiar location.” The figures show the items that were often more difficult for the ASD sample. However, there are no clear patterns relating when a Daily Activity item is “easy” to when the child was reported to have “most responsibility” in the corresponding Responsibility item.

Discussion

The present analysis found a clear difference in skill acquisition as measured by Daily Activities and task management as measured by the Responsibility items between the ASD and the normative samples. For both groups there was a difference in the age when a child was reported able to complete a component of the task and when he or she took most or full responsibility for the task. However, consistent with the literature, there were differences between the ASD and normative samples, with the ASD sample showing a delay.

The fine motor demands of most of the Daily Activity tasks with an age gap between the two groups, or that the majority of the ASD sample never found “easy” is interesting in light of reports that children with ASD have higher rates of motor impairment (Whyatt & Craig, 2011; Noterdaeme, Wriedt, & Hohme, 2010). Further research is needed to examine whether fine motor impairments are related directly to these functional performance limitations.

The impairments in executive functioning common to the *ASD population* may

directly relate to the results found in this study (Gilotty, 2002). Managing a complex daily task requires executive function skills; being able to complete an individual activity such as putting on a shirt does not directly correlate to being able to organize and complete everything needed to get ready in the morning. A child with ASD may have the ability to physically do the things required to get ready in the morning, but our results suggested they often are unable to organize and plan the various steps needed to take over responsibility for this task. This finding is consistent with other research has showing that most individuals with ASD do not achieve functional independence even in adulthood (Brown et al., 2011). The PEDI-CAT Responsibility items include many tasks required for independent living. The item analysis indicates that fewer than 50% of this ASD sample was reported to take most responsibility for 37 of these items. However, it is important to note that even in the normative sample, many items in the Responsibility domain have a “late” age of taking “most responsibility”.

Additional research is needed to determine the executive functioning skills required to integrate daily activity task skills to manage a complex responsibility task. Information on this question will be important to help determine effective interventions to facilitate transfer of responsibility from parent to child.

Limitations

The ASD sample was not categorized by level of IQ or communication impairment for analysis as sample sizes within each age group would have been too small. Therefore it is not known whether differences in when Daily Activity items were

considered “easy” or when the child took “most responsibility” might have varied along these dimensions in the ASD sample. Although the gender distribution was typical of ASD, the study sample was largely male and therefore results may not be representative of the females with ASD. For some Responsibility tasks, only a few related activity items were identified and these items were not always central to managing the Responsibility (e.g., putting on watch vs. managing time). The gaps identified could be related to difficulty performing activities that are not included in the PEDI-CAT Daily Activity item set. Therefore, these results may not specifically identify activities that should be the focus of intervention to address management of the overall task.

Implications for Occupational Therapy Practice

Occupational therapists working with the individuals with an ASD should understand that mastery of a specific activity will not necessarily translate to more independence in the overall task of which it is a part. Taking responsibility for a task requires additional competencies beyond being able to complete all of the individual activities of the task.

Table 1. Demographic Characteristics

Characteristic	Without Disabilities (N=2,205)	Autism and Co-Occurring Conditions (N=365)
Gender		
Male	1,126	304
Female	1,078	61
Race		
White	1,427	312
Asian	30	7
Black	241	5
Other	736	41
Family Income		
less than 10,000		14
Between 10-29,999		32
30-59,999	743	89
60-99,999	833	95
100-129,999	462	52
above 130,000		50
prefer not to answer	166	33

Table 2. Characteristics of ASD Sample (n = 365)

Characteristics	N
Reporter	
Mother	342
Father	23
Autism Diagnosis	
Autism	190
Asperger	93
PDD-NOS	81
Don't know	1
IQ	
Above average	62
Average	84
Borderline	52
Mild	39
Moderate	17
Severe	13
Unknown	98

Table 3. Age Groups

Age Group	Ages (years)	Normative (N)	ASD (N)
1	3-5	310	47
2	6-8	230	66
3	9-11	306	64
4	12-14	329	79
5	15-17	324	69
6	18-20	320	30

Table 4. Daily Activity items achieved at same age in both groups

Daily Activity Item	Age Group
Drinks from Bottle or spout cup	1
Swallows pureed/ blended/ strained foods	1
Finger feeds small or bite-size pieces of food	1
Holds and drinks from an open cup or glass	1
Holds and eats a sandwich or burger	1
Feeds self with spoon (minimal spilling)	1
Drinks liquids using a straw	1
Turns the water on and off at sink	1
Removes socks	1
Removes pants with elastic waist	1
Puts on sunglasses	1
Opens door lock using key	3
Pulls tab on a soft drink can	3

Table 5. Daily Activity items with one age group difference between groups

Daily Activity Items	Normative	ASD
Feeds self with fork (minimal spilling)	1	2
Rubs hands together to clean	1	2
Takes off a t-shirt	1	2
Puts on a t-shirt	1	2
Puts on slip-on shoes	1	2
Uses a computer mouse to click on icons or links	1	2
Inserts a straw into a juice box	2	3
Stirs to mix ingredients	2	3
Squeezes plastic bottle to obtain ketchup, syrup,	2	3
Removes lid from plastic food containers	2	3
Cleans body thoroughly in bath or shower	2	3
Wipes self with toilet paper after a bowel movement	2	3
Connects and zips zippers that are not fastened at the bottom	2	3
Puts on winter, sport, or work gloves	2	3
Uses a TV remote control	2	3
Operates a video game controller	2	3
Uses a computer keyboard to type	2	3
Presses buttons to operate a keypad such as phone or ATM	2	3
Removes a single bill from wallet	2	3
Puts on Deodorant	3	4
Pours liquid from a large carton into a glass	3	4
Unscrews the lid on a tight or new jar	4	5

Table 6. Daily Activity items with two or three age group differences between the groups

Daily Activity	Normative	ASD
Closes a bottle with a twist-off cap	1	3
Puts on socks	1	3
Uses a knife to butter bread and spread jam	2	4
Pulls open a sealed bag of snack food	2	4
Opens sealed cardboard food boxes	2	4
Wipes nose thoroughly with tissue	2	4
Puts toothpaste on brush and brushes teeth thoroughly	2	4
Dries hair with a towel	2	4
Obtains shampoo, washes and rinses hair	2	4
Puts on and buttons a front-buttoning shirt	2	4
Puts on and fastens pants	2	4
Fastens belt buckle	2	4
Tucks in shirt or blouse	2	4
Wipes a counter or table	2	4
Stacks breakable plates or cups	2	4
Puts a bandage on a small cut on hand	2	4
Ties shoelaces	2	5
Empties food from mixing bowl to baking pan	3	5
Cuts with scissors to open hard plastic packaging	3	5
Replaces (unscrews and screws) the bulb in a table lamp	3	5
Cuts vegetables or meat with a fork and table knife	3	6
Fastens watch band	3	6
Changes pillow case on pillow	3	6
Tightens loose screws using a screwdriver	4	6

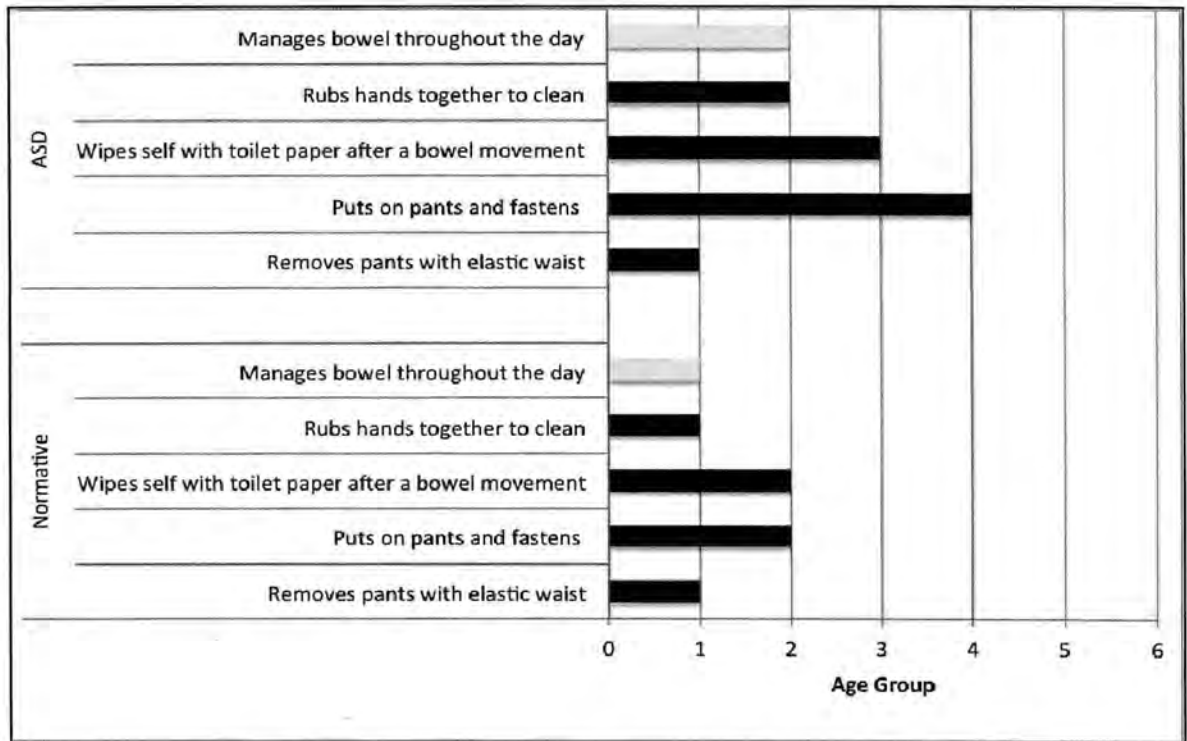
Table 7. Daily Activity items never reported “easy” in the ASD sample

Daily Activity Item	Normative
Chops or slices hard fruits or vegetables	3
Trims fingernails on both hands	3
Inserts laces into sneakers or boots	3
Peels foods such as potatoes or carrots	4
Uses a can opener to open a can	4
Trims toenails on both feet	4
Fastens a necklace or chain	4
Opens childproof medicine or vitamin containers	4

Table 8. Responsibility Items for which the ASD sample did not achieve “most” responsibility

Responsibility Items ASD sample never takes Most Responsibility	Age Most Responsibility Normative
Keeping electronic devices working	3
Coping with stress/worry/anger	3
Packing items for overnight	3
Planning/following weekly schedule	4
Choosing/arranging social interactions	4
Developing/following plan to reach goal	4
Prioritizing multiple goals	4
Maintaining cleanliness of living space	4
Taking care of minor health needs	4
Using internet safely	4
using knife and grater safely	4
Supervising/caring for another person	4
Following a recipe	4
Managing kitchen appliances	4
Informing home/school/work when absent	5
Managing daily expenses	5
Seeking out/joining club/group	5
Tracking spending/managing money	5
Managing health appointments	5
Communicating health needs	5
Taking precautions to avoid STD/pregnancy	5
Following health/medical treatment	5
Seeking medical help	5
Making healthy choices	5
Taking precautions to protect personal information	5
Traveling safely within community	5
Determining safety of new location	5
Buying clothing	5
Cleaning/caring for clothes	5
Using safe food handling practices	5
Eating/drinking appropriate foods	5
Completing legal/personal paperwork	6
Resolving errors in personal business	6
Paying bills	6
Locating services/supports	6
Organizing papers/information	6
Managing food needs for week	6

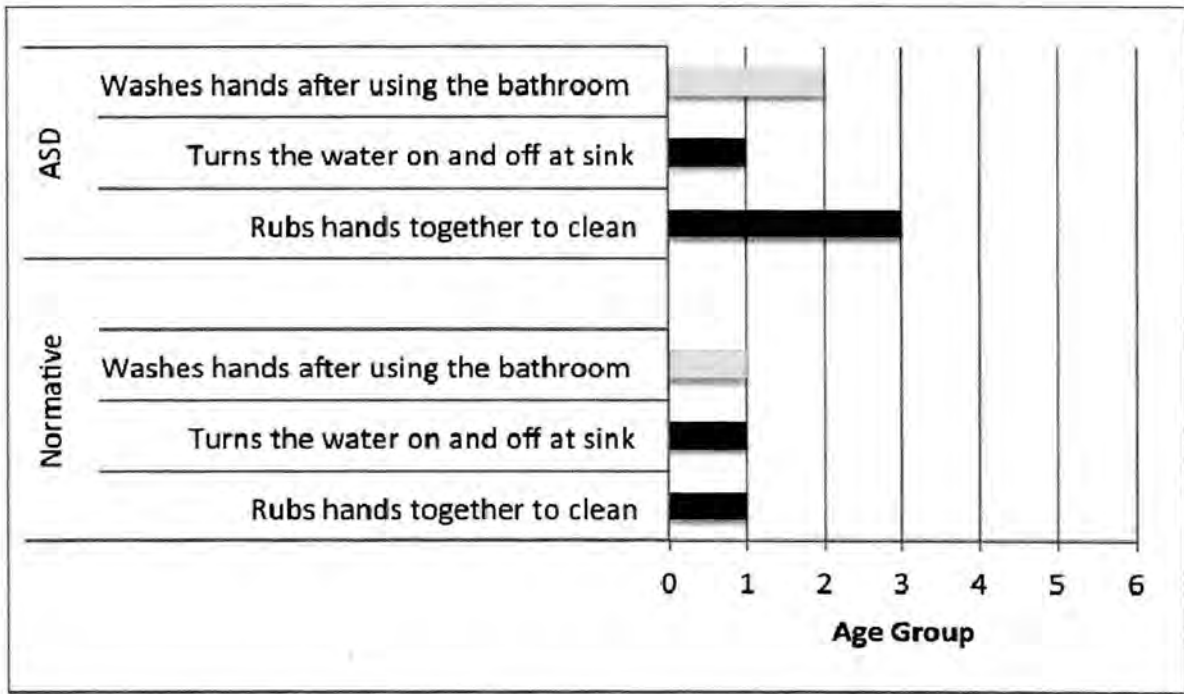
Figure 1. Responsibility item Manage Bowel with associated Daily Activities




Key:

- Responsibility
- Daily Activity

Figure 2. Responsibility item Wash Hands with associated Daily Activities



Key:

 Responsibility


 Daily Activity

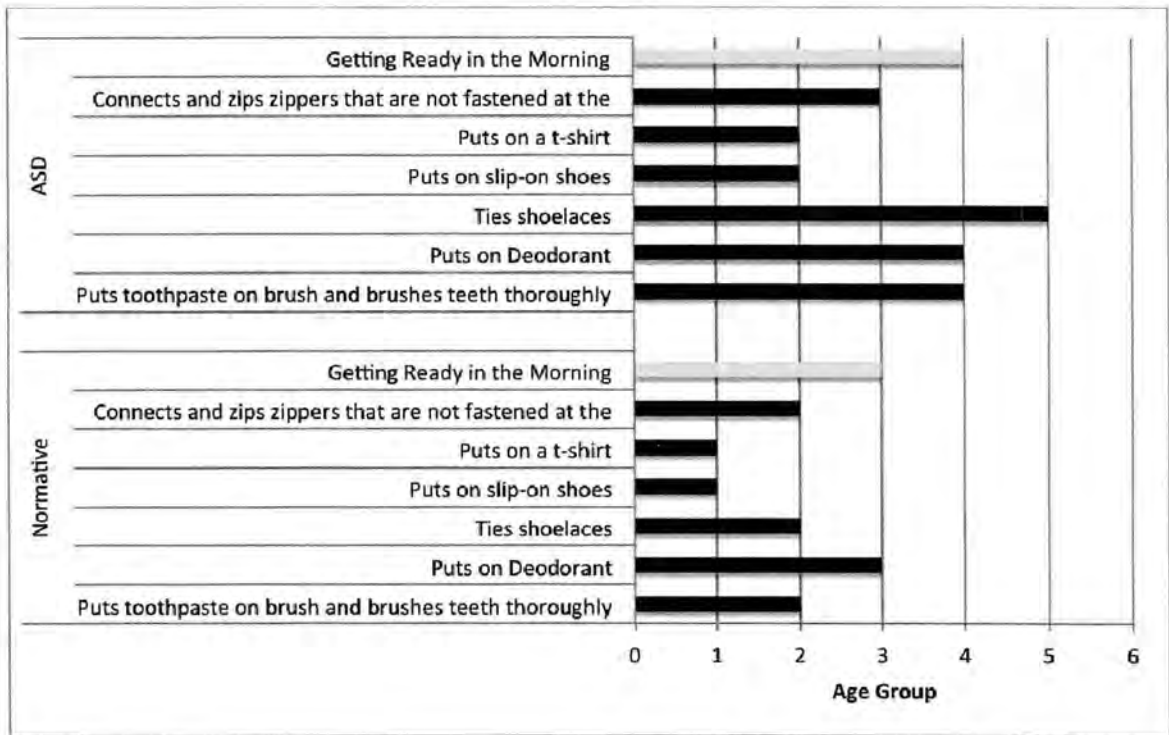
Figure 3. Responsibility item Fix Meals with associated Daily Activities



Key:

- Responsibility
- Daily Activity

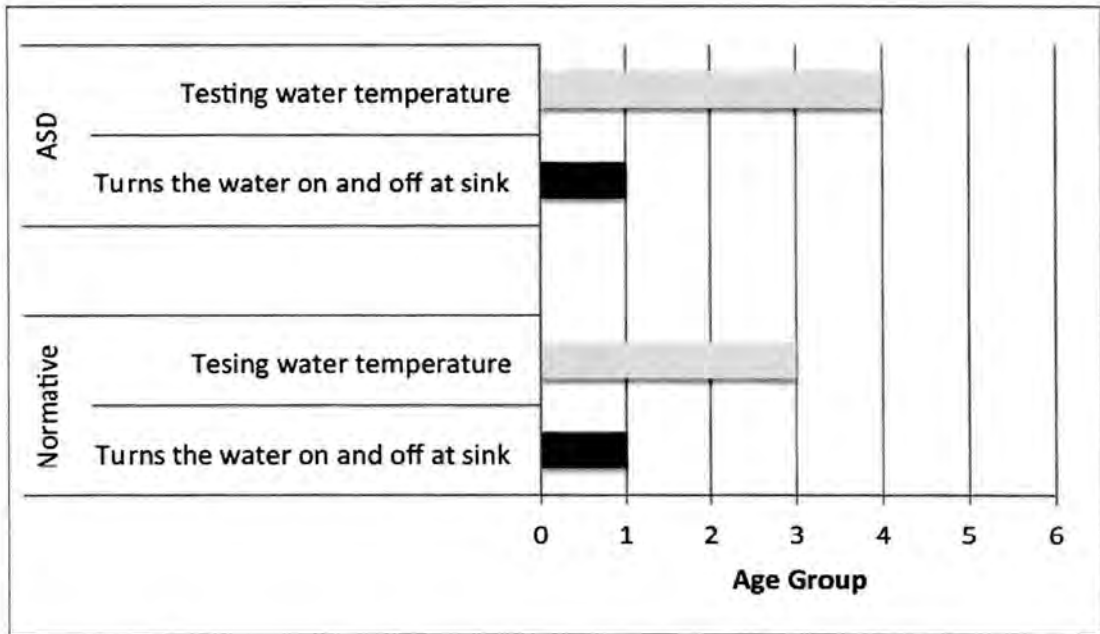
Figure 4. Responsibility item Get Ready in the Morning with associated Daily Activities



Key:

- Responsibility
- Daily Activity

Figure 5. Responsibility item Test Temperature with associated Daily Activity




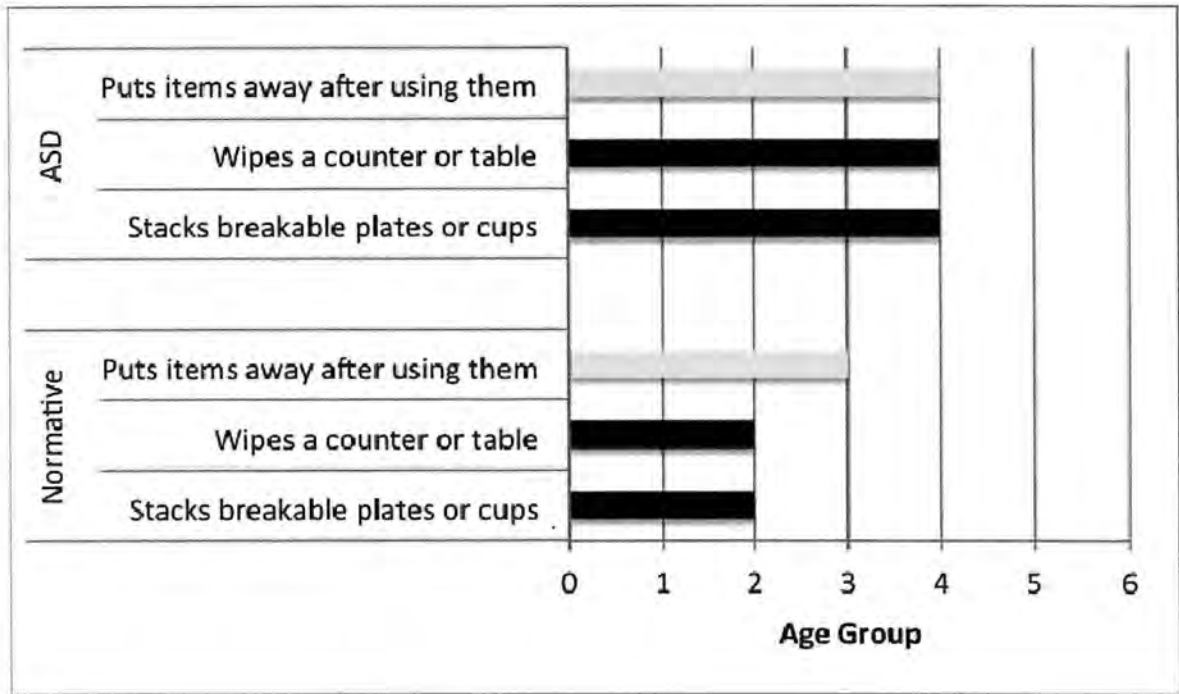
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 Daily Activity

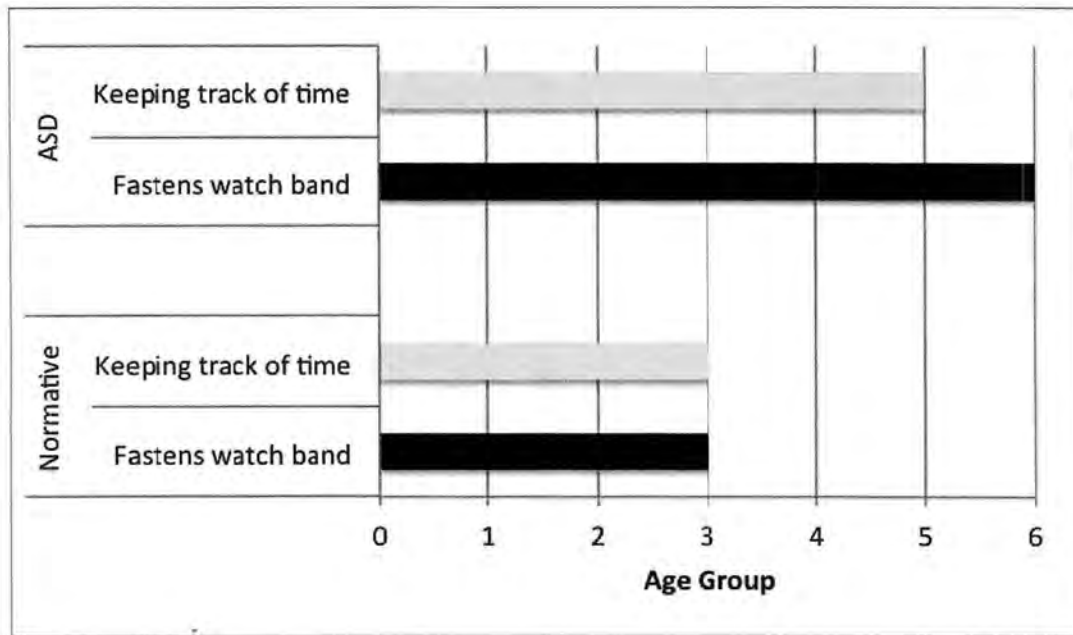
Figure 6. Responsibility item Put Items Away with associated Daily Activities




Key:

- Responsibility
- Daily Activity

Figure 7. Responsibility item Keep Track of Time with associated Daily Activity



Key:

 Responsibility


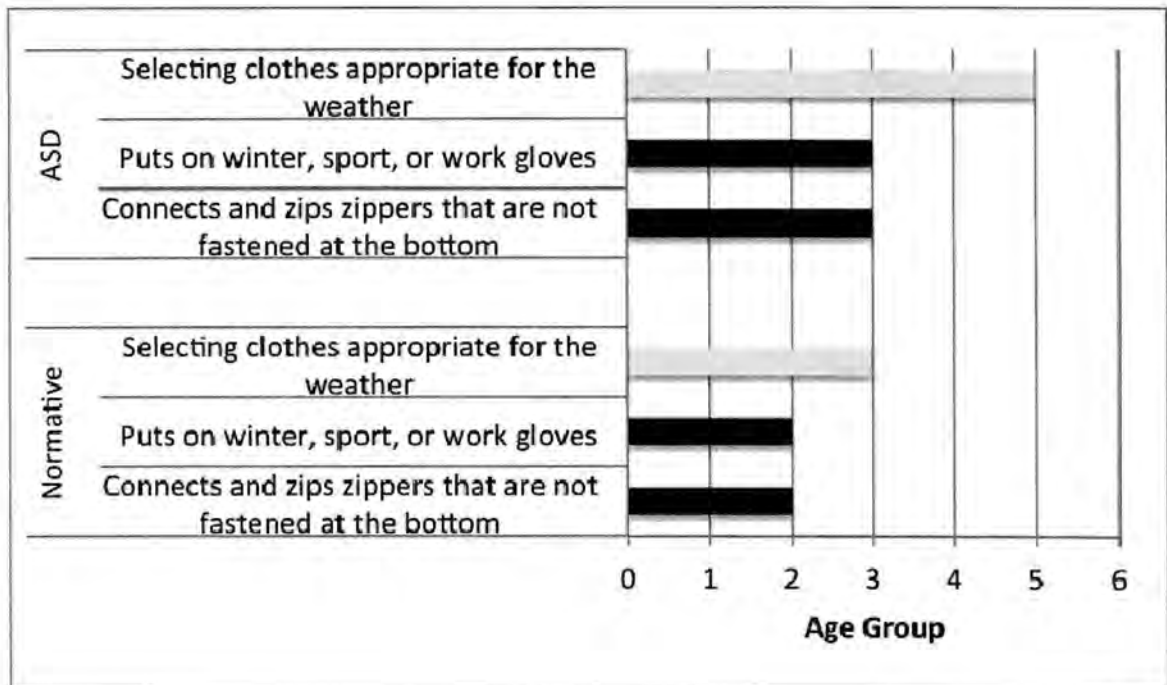
 Daily Activity

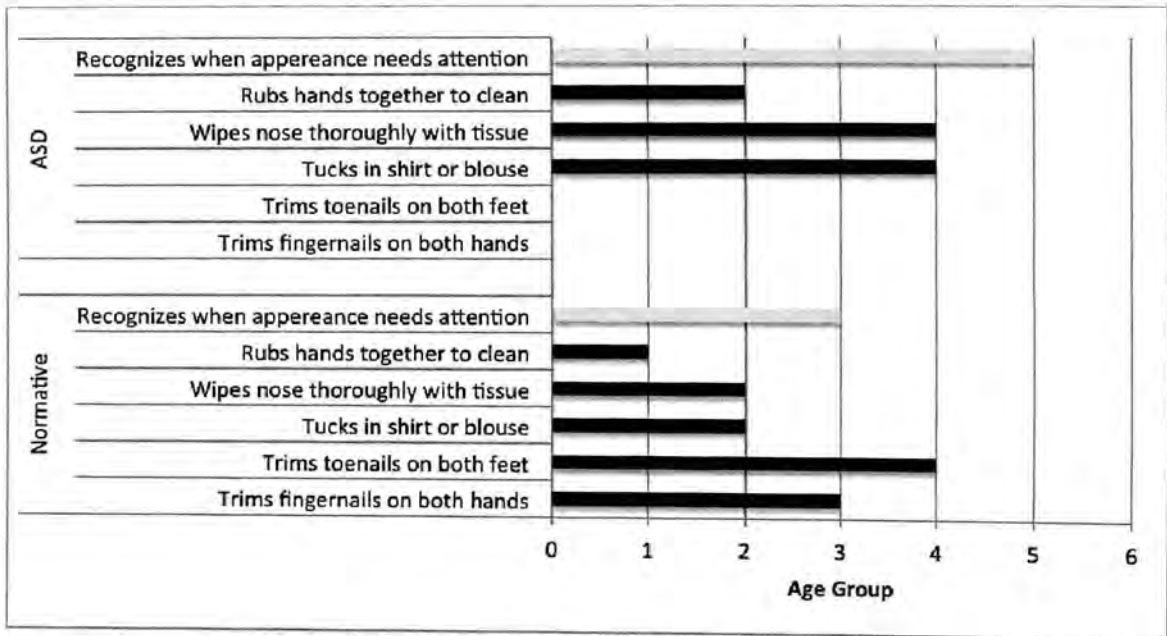
Figure 8. Responsibility Select Appropriate Clothes with associated Daily Activities



Key:

-  Responsibility
-  Daily Activity

Figure 9. Responsibility item Recognize Appearance with associated Daily Activities



Key:

- Responsibility
- Daily Activity

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CURRICULUM VITAE

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