



## Adults with autism in India: A mixed-method approach to make meaning of daily routines



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### ABSTRACT

Although individuals with Autism Spectrum Disorder (ASD) have been diagnosed in India for over fifty years, virtually nothing is known about the social circumstances of adults, their daily lives, and their families. Where are adults with autism? How do they spend their time? Who are they with, and what are they doing all day? A mixed-method approach was used to obtain information on daily routines of 54 adults with ASD living in New Delhi, India, and about parent levels of stress associated with these routines during a study collected from January through June, 2013. Whether or not they attended a structured setting during the day (59% did so), adults engaged in some 20 activities both inside and outside their home. Contrary to our expectations, most adults were not “hidden” and were out in public at least on occasion. Higher functioning adults were more likely to attend a structured setting, but parents described challenging behaviors, both adult and parent preference, and lack of options as reasons that adults stayed home. The amount of time adults spent outside their home was not associated with parent reported stress, but stress was significantly higher for mothers who were employed. Most families described adaptation to caring for their adult children. A partnership with an Indian nongovernmental organization provided mechanisms to amplify our research findings, making them meaningful to our participants and others.

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The importance of understanding adult trajectories and a life-span perspective of Autism Spectrum Disorder (ASD) has gained prominence in recent years. As the number of children identified with ASD grew during the 1990s (Newschaffer et al., 2005), these increasingly large cohorts of children have now reached adulthood. There has also been an increase in diagnosis of ASD in adults (e.g., Eriksson et al., 2013; Pilling et al., 2012). Research in the early 2000's laid out a number of key issues, such as ways to assess quality of life for adults with ASD, understanding employment opportunities, family needs during the transition to adulthood, and comparisons between adults with autism living at home or in non-family residential settings (Krauss et al., 2005; Seltzer et al., 2000). International and US perspectives on families of those with intellectual disability have also mapped out a range of topics (Glidden and Seltzer, 2009).

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Over the past decade, there has also been an increase in studies that address ASD in a cultural context. Anthropologists, sociologists and others in the social sciences are focusing on autism as never before. In the year 2011 alone, for example, reports on autism came from countries as diverse as Brazil, China, Colombia, Croatia, Egypt, India, Iran, Libya, Nepal, Nigeria, Oman and Pakistan (Daley et al., 2013). Almost without exception, this new wave of studies—sociological, anthropological, and from diverse countries—has focused on how society and culture intersects in the lives of children and youth with ASD, or on parent experiences of raising young children. While global perspectives of adults with sensory and physical disabilities have been well-documented (e.g., Priestley, 2001), research related to adults with ASD in low and middle income (LAMI) countries is virtually nonexistent. The only published reports we were able to identify come from the country of focus of our current work: India.

In fact, in no other LAMI country has ASD received as much attention as in India. Dozens of organizations and schools cover both major cities and smaller towns, national awareness campaigns have flourished, and before a character with ASD ever appeared on

U.S. airwaves, India had an extremely popular serial featuring a girl with autism, *Aap Ki Antara*. The majority of recent policy focus, however, has been on children rather than adults (Girimaji and Srinath, 2010). Similarly, research publications from India date back more than 50 years (Daley et al., 2012), yet a total of only eight articles have been published on adults, all of them case studies (Bannerjee, 1975; Abhyankar et al., 1981; Duggal et al., 2001a, 2001b; Chaudhari et al., 2008; Arora et al., 2011; Barua, 2007; Sharma et al., 2013). These reported cases have generally featured adults with savant abilities or psychotic disorders, with no significant studies focusing on daily lives of adults and their families. We know, of course that most adults are neither “Rainmen” nor are they psychotic. Who are these adults, and how do they spend their time? Whom are they with, and what are they doing all day? Does this differ if they are high or low functioning? Is it more stressful for the parent when an adult is home all day, or when he has some place to go? And what would be most helpful to parents and adults in urban India right now? These questions can be bundled into a framework often referred to as daily routines.

### 1. Daily routines as a window into adult lives

Daily routines are a key unit of analysis for ecocultural theory (Harkness et al., 2011; Weisner, 2002). They are the simple activities of daily life (waking up, eating breakfast, listening to music, going to the park, going for a drive) and include many features that describe shared cultural practices: Goals and values for that activity; the people and relationships in the activity; the resources (social and material) needed to do it and how and why resources are allocated; the norms or scripts for doing that activity; and the frequency, regularity, consistency with which it is done. Super and Harkness (1997) describe these everyday routines, activities and practices as part of the niche of child and human development, which includes resources, shared cultural beliefs, and everyday routines and practices, each of which being essential to understand human development in context. For any of us, just as for those adults with ASD in Delhi who are the focus of our study, ASD-specific routines and cultural beliefs are important indicators of culture on their lives.

For families with adults with ASD, there is special value in understanding the daily routine. The pervasiveness of the effects of mobility restrictions, and the use of routines as a coping strategy for caregivers are found for adults with ASD, as they are for the elderly (Wiles, 2003). Of course, it is a challenge to gather evidence on the cultural and emotional significance of recurring daily activities for someone with ASD because their disability includes reduced social and intersubjective awareness, reduced communication, and fixed and repetitive behaviors – all of which are involved in shared and meaningful joint daily activities with others. As with caring at home for the frail elderly, nonetheless, adults with ASD have a wide range of abilities, and their parents can report on some aspects of their experience and meaning of their activities.

In addition, we know from past research (Albin et al., 1996; Bernheimer and Keogh, 1995) that an intervention or support for a family with a disabled member will be most effective when it fits into the daily routine. By taking apart and highlighting the ordinary activities of adults and their families, we can better see where there are gaps and cracks—where the routines are not satisfactory and what would make life easier for families in India. Through daily routines, we can identify potential levers of change, and a family routine can be adjusted in ways that may improve the well being of adults and family members alike, even when institutional change is difficult and individual change is slow.

For adults with ASD and their caregivers, well-being (not simply normative outcome scales of functioning, or fulltime work and

independent family life, which many adults are unable to attain) provides a meaningful contextual concept to understand outcomes. Well-being captures the capacity, ability and extent to which, the adults with ASD engage in the activities deemed desirable in their community, and the psychological experiences produced by such engagement (Weisner, 2009). Routines have some of their force through being frequent, predictable, and part of a recurring pattern of activity that is meaningful and which, of course, can be particularly comforting for an adult with ASD.

We approached the topic of daily routines with open minds regarding what activities might reflect an “optimal” outcome. While we knew of vocational training programs and job skills training for higher functioning adults in India, we also knew that we would meet many adults who did not leave their homes during the day and who had limited social contacts. Rather than view this “homeboundness” as a poor outcome, we hoped to learn why these adults stayed home, whether this routine worked, and whether there was something these families needed that they did not have. This paper addresses these questions using a mixed-methods approach, integrating observations, interviews that collected both open-ended data as well as closed-ended questions, standardized assessments, and questionnaires.

## 2. Methods

### 2.1. Setting and participants

Participants were fifty-two families (54 adults with ASD) living in New Delhi and the National Capital Region (NCR) of India, an area of 22.1 million people, and the world’s second largest city. Families were recruited to participate through multiple avenues. A database maintained by a national autism organization, Action For Autism (AFA) was used as the primary recruitment tool. Contact was initiated with 78 of these families, selected to represent different geographic areas, both women and men, and to reflect all age groups. For 24 of these families, contact information was incorrect and no further recruitment was possible. Ten families were ineligible, primarily because the date of birth incorrectly identified the individual as an adult. One adult was deceased. Five families received the information, and were not interested in participating, and 6 families were interested, but a visit could not be scheduled before the end of the study period. Thus, a total of 32 families were successfully recruited through the AFA database. Seven families were recruited through other programs for adults located in Delhi, through public autism events, and through a parent support group. Lastly, an additional 15 families had participated in a 1996 study of autism in India (Daley, 2004) and were invited to join the study. Adults needed to be at least 18 years old and have at least two of the following: a past diagnosis of an ASD; meet the cutoff for ASD based on the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Lord et al., 2012); or meet the cutoff for ASD on the Social Responsiveness Scale, Second Edition (Constantino and Gruber, 2012), which was completed by parents. While we make no claim that our sample is representative of adults with autism in New Delhi, we were successful in our goal to include adults with a range of abilities, backgrounds, daytime settings, and to include families both with and without previous contact with formal organizations.

### 2.2. Characteristics of the adults with autism

Adults in the study ranged in age from 18 to 44 years old ( $M = 25.1$  years,  $SD = 6.2$ ), and 44 (82%) were male. All adults lived with their parents; one adult was married. This reflects the situation throughout India: The overwhelming majority of children and adults with developmental disorders, including ASD, live with their

families. Across the sample, 28% of the adults were only children. Adults had a variety of daytime settings, although they predominantly stayed at home (41%) or attended a special program or center for adults with disabilities (37%) for at least three hours a day. A small number (7%) were receiving job coaching, and 9% were attending either a regular high school or higher education. One adult in the sample was working, and two adults spent time at their mother's place of employment but were not employed or attending school themselves.

The overall skill level of these adults ranged widely, from adults who had no language and limited independent living skills (e.g., were not toilet trained) to adults who were studying in college and law school and one who was competitively employed. To describe adult language level, a 7-point scale was created using information from administration of the ADOS, observation of the adult within the broader interview period, and information provided by parents. Language level and overall adaptive skills were highly correlated ( $r = .87, p < .0001$ ). In the analyses, we combine adults with language levels 0–4 into a *low language* group and levels 5–6 into a *high language* group. Twenty four percent of the adults in the study were nonverbal or used only single words, and 32% had relatively complex speech, with 44% in between. Adaptive skills were assessed through interviewing the parents using the Daily Living Skills domain of the Vineland Adaptive Behavior Scales, Second Edition (VABS-II, Sparrow et al., 2005). As noted in previous studies (e.g., Manohari et al., 2013), some items as phrased in the VABS were not applicable to this population, and other items were

dropped because no or very few adults had the skill, leaving 99 items in the subdomains of Personal, Domestic and Community. Analyses that rely on the VABS are based on quartiles. Table 1 presents data on adult characteristics.

### 2.3. Characteristics of families

Families in the study were predominantly Hindu (82%). Among the families, 65% were nuclear (consisting of the adult, parents, and any siblings) and the remainder had one or more extended family members living in the same house, with an overall average household size of 4 (ranging from 2 to 7). Families in this project tended to be relatively well off; about 56% of families reported a household income of 75,000 rupees or greater per month (about \$1200). Many families in India, particularly with this economic background, have servants working in their households either during the day or full time, for example, doing the cooking and cleaning. In our sample, 67% of families had either part-time or full-time help, and 26% had both. Half the mothers and three-quarters of the fathers in this sample worked at least part-time outside the home (see Table 2).

### 2.4. Procedures

All families were interviewed in their homes, with either two or three members from the research team participating in each visit. Ethical approval was obtained for the study by the Institutional Review Boards of UCLA, and the study protocol was also reviewed and approved by the AFA IRB. Consent was obtained from families first during the recruitment phase, and then again at the home visit. Consent was separately obtained from high functioning adults. For nonverbal adults, parents provided consent, and interviewers subsequently made decisions about adults' willingness to participate based on behavior of the adults. All data were collected

**Table 1**  
Adult characteristics (N = 54).

Adult characteristics	N	%
ASD eligibility basis		
ADOS, SRS and past diagnosis	37	68.5
ADOS + SRS only (never officially diagnosed)	5	9.3
Past diagnosis + SRS (ADOS not completed)	5	9.3
Past diagnosis + ADOS (SRS within normal limits)	4	7.4
Past diagnosis + ADOS (SRS not completed)	3	5.6
Sex		
Male	44	81.5
Female	10	18.5
Age		
18–20	19	35.2
21–25	16	29.6
26–30	9	16.7
31+	10	18.5
Birth order		
Only child	15	27.8
Eldest with younger siblings	21	38.9
Younger with elder siblings	18	33.3
Daytime setting		
Stays at home	22	40.7
Special school: Special section, or special vocational training	20	37.0
Mainstream school: Special section	1	1.9
Higher education setting	4	7.4
Job training	4	7.4
Competitively employed	1	1.9
Other	2	3.7
Language level		
0: No spontaneous words or word approximation	9	16.7
1: Single words only	4	7.4
2: Occasional phrases only, mostly single words	11	20.4
3: Mostly simple phrases of 2–3 words	9	16.7
4: Mostly phrase speech of three or more words per utterance, some grammatical markings and non elliptical phrases	4	7.4
5: Some relatively complex speech with two or more clauses but with recurrent grammatical errors.	2	3.7
6: Uses complex sentences with two or more clauses in a largely correct fashion	15	27.8

**Table 2**  
Household and family characteristics (N = 52).

Geographic area of Delhi & NCR		
North <sup>a</sup>	5	9.6
East <sup>b</sup>	6	11.5
South	14	26.9
West <sup>c</sup>	9	17.3
Central <sup>d</sup>	2	3.8
NCR-Haryana <sup>e</sup>	9	17.3
NCR-Uttar Pradesh <sup>f</sup>	7	13.5
Religion		
Hindu	40	76.9
Muslim	2	3.8
Christian	4	7.7
Sikh	3	5.8
Jain	1	1.9
Two different religions followed	2	3.8
Household type		
Nuclear	35	67.3
Extended or Joint	19	36.5
Reported monthly household income (in Rupees)		
Less than 25k	6	11.5
25k to 50k	10	19.2
50k to 75k	7	13.5
75k & above	29	55.8
Mother employed outside the home	26	50.0
Father employed outside the home	39	75.0

<sup>a</sup> North includes the administrative districts of North, North West.

<sup>b</sup> East includes the administrative districts of East and North East.

<sup>c</sup> West includes the administrative districts of West and South West.

<sup>d</sup> Central includes the administrative districts of Central and New Delhi.

<sup>e</sup> NCR-Haryana consists of families in Gurgaon and Faridabad.

<sup>f</sup> NCR-UP consists of families in Noida, Greater Noida and Ghaziabad.

between January and June 2013. Interviews were conducted in the language of choice of the parent, and lasted between 2 and 5 h.

To obtain detailed information about daily routines—the “what, where and with whom” of each adults' typical day—parents began describing activities from the time the adult usually awoke each morning through when the adult went to sleep. As the parent walked through a typical day, the interviewer recorded in half-hour increments 1) what the adult did, 2) where this took place, and 3) whether the adult was with anyone. Following the visit, the interviewer used this grid and transcriptions of the interviews to record a) the waking and sleeping time, b) hours spent napping, c) hours spent outside the home, d) hours spent outside the home in a structured setting, e) hours spent inside the home in private space (e.g., a bedroom), and f) the hours spent with different family members and others. These points provide numeric data for the analyses.

Using the transcripts of the description of the daily routine, we extracted all references to activities that adults were reported to engage in (e.g., watching TV, going for a walk, using the computer). Detailed information was also obtained about the type of setting adults were attending when relevant.

A set of questionnaires, available in both Hindi and English, was left for parents to complete separately and on their own. Data from one of these questionnaires, the Parent Stress Index-Short Form (PSI-SF; [Abidin, 1995](#)) are reported in this paper. The PSI-SF consists of 36 items and uses a five-point Likert scale from strongly disagree to strongly agree, with three subscales, called Parental Distress (PD), Parent–child Dysfunctional Interaction (PCDI), and Difficult Child (DC), each containing 12 items. The PSI-SF has been used with parents to examine a wide range of topics, and it has also been previously used in Indian populations, including parents of children with ASD ([John, 2012](#)).

### 3. Findings

Broadly speaking, many of the ways that adults spend their free time sound very familiar and like adults with or without disabilities in many places: watching TV, listening to music, using a computer or iPad, doing household chores. [Table 3](#) shows the percent of the sample that engages in each of 20 reported activities for at least 30 min during their day.

One activity was reported by 44% of families—going for a walk—and many of the families who didn't mention this had adults who were already out in the community through other activities.

**Table 3**  
Percent of sample engaging in activities during a typical day.

Activity	N	Percent of sample
Watch TV	38	70.4
Attend structured setting	30	55.6
Listen to music	29	53.7
Nap	25	46.3
Talk/interact with others	25	46.3
Go for a walk	24	44.4
Lie or sit around	23	42.6
Read or write for leisure	21	38.9
Use computer or iPad	20	37.0
Exercise & physical activity (more than a walk)	18	33.3
Roam	17	31.5
Household chores	16	29.6
Engage in repetitive or ritualistic behavior	15	27.8
Study or do academic work	10	18.5
Go for a drive with family	9	16.7
Go shopping or to market	8	14.8
Meditation/yoga/prayer	7	13.0
Paint or draw	4	7.4
Play or practice music	4	7.4
Other	5	9.3

The significance of this is that, despite the stigma still present in India, parents are consistently bringing their sons and daughters into a public space. When asked about changes from when her son was younger, the immediate comment from the mother of 31-year-old Akhil was, “Before, kids like these didn't go out, but now they can.” (All names in this paper are pseudonyms). Going to familiar places means there is more at stake—these are not just strangers whose comments can be easily dismissed. Akhil's mother continued, “Everyone knows that he does [his unusual hand motions] sometimes. It's OK, everyone asks him, how are you, Akhil? How have you been doing?” In many of the stories we heard, the consistency of the nearby park, local shop or neighborhood “loop” is precisely what made a daily outing doable for families like Akhil's. The stigma they may have once felt seems to have lessened over time, at least in the proximity of their own neighborhoods.

We also observed that many adults in our study have interests that fit extremely well into the family routine. Though Rakshak's language skills are limited to using only occasional phrases, he is fascinated by religion and spends a significant amount of time watching religious programs, listening to religious music, and searching the web for information on Hindu gods. His mother encourages his interest; she shares his passion and respects what she interprets as his piety. Pulkit, too, has an interest in Sathya Sai Baba, a popular Hindu guru. His interest in devotional songs and riveted attention to these made his mother think more closely about his interest in music and led to his musical training, since she herself runs a dance studio. Now, they have been able to combine their shared interest and Pulkit will often perform as a singer with her dance students.

One of the most touching descriptions of complementary interests and routines came from 25-year-old Ashutosh. Ashutosh is minimally verbal and does not leave his home, but he keeps the house in order all day long, waking as early as 5:30 am to give his mother her clothes from the cupboard. Throughout the day, he is folding, straightening, and cleaning until 10:30 at night when his parents lay down and “he gives us blankets, makes us comfortable, then he switches off the light and all the other lights and goes to his room.” His favorite activity is receiving the ironed bundles of his family's clothes from the launderer, sorting and hanging these in the different cupboards. “That's two, three days work for him,” his mother explained. While compulsive, it is at the same time functional to the family and, Ashutosh's parents believe, also enjoyable to him. Though Ashutosh used to attend a center, his parents are not actively looking for some place for him to go during the day any more, and there is no part of his day they wish for him to change: “if he is happy, we are happy,” his mother said.

The experience of Ashutosh is not true for all adults, however. In many cases, the descriptions we heard reflect the challenge of filling up a day's worth of time. “Lying around” “idle time” and “roaming around” were identified as ways that more than a third of all adults spend time during their days. Pranav does not have any place to go to during the day and “he gets bored, then he keeps asking for chocolates, for cola, for noodles, all kinds of things—everything that comes into his mind.” Anmol's parents admit that his day is “not very exciting,” although his habit of sleeping until 10:30 in the morning has suited the family fine because it gives his father time for himself in the morning. Sonu, a lower functioning adult, goes for a two-hour walk with his father each day but when he is at home “he just roams about here and there,” chewing on a stick or on his collar. Prakash spends more than five hours a day flicking or tapping an object repetitively, and, similar to both Pranav and Anmol, also spends time throughout the day masturbating, an activity mentioned by a number of families. Adults' inability to occupy themselves in a way that their parents perceived as meaningful was a source of frustration for many, who

found it exhausting to try to force their adult children to engage in an activity “just to be doing something.” Similar challenges have been identified in other studies of families of those with disabilities (e.g., Mactavish and Schlein, 2004).

Overall, regardless of their level of functioning, adults spent approximately three-quarters of their time awake in shared family spaces—rooms that are intended for use by many family members, such as the living room, kitchen, or eating area. It is encouraging that adults with autism are not being not hidden away in back corners of their homes, yet physically being in a room that is shared does not necessarily mean that the adults are sharing social experiences. About 60 percent of the time that they are awake in their homes, adults were not reported to interact with others, so shared experiences are not necessarily high.

A broader distinction among the adults in our sample is whether or not the adult attends a structured daytime setting. As described above, 22 of the 54 adults in our study do not have a formal place they go to during the day. These adults have significantly lower adaptive skills,  $t(50) = -3.239, p = .002$  and lower language skills,  $t(51) = -3.265, p = .002$  than adults who have a structured setting. When adults attend a setting, the amount of time ranges from 3 to 10 h per day ( $M = 5.8$ ), and from between four and six days a week. While some parents did not know what took place at the centers, others reported that adults learned basic cooking skills, spent time on the computer, exercised, and engaged in craft-making activities, such as decorating paper to be sold at the holidays.

Adults who stay home were reported to sleep as late as noon, whereas adults who leave wake no later than 8:30 in the morning. Adults who stay home sleep significantly more in a given day, an average of 10 h a day,  $t(51) = 2.336, p = .023$ , and 60% of the adults at home take naps. Adults at home also spend more time alone—an average of 5.3 h,  $t(51) = 1.156, p = .048$ . In addition, we found these adults spend most of their days inside their homes, on average, spending 22 h a day inside. Six adults in our study did not step outside their home at all on a typical day.

Parents provided different reasons for the time spent inside and for the absence of a structured setting. One of the most common explanations was that their son or daughter either actively resisted going any place or were simply just happier at home. Sagar is 26 years old now, and has not attended any school since age 13. Sagar's mother firmly believes this has been best for her son, who is happy to be home in a “normal” environment, where he is treated “like any regular guy.” Akshat's mother isn't as sanguine about his refusal to leave home; she recognizes the limitations it creates for the family, and wonders if she has catered to his desire too much and now has “fallen in a rut” by not pushing him more. On the other hand, she sees that he can happily occupy himself for hours creating pictures on the computer, and that he seems fulfilled by doing this.

Some adults are prevented from spending more time outside their home not by preference but because of behaviors that are challenging for others to handle. These behaviors include hitting, throwing objects, pushing, removing clothes, sexual behaviors and vomiting, as well as seizures, other medical problems, and not being toilet trained. Gitanjali's mother ties her to chairs and beds to keep her from injuring herself during a seizure, which occur 30–40 times a day, and doesn't let her out of arms' reach. Shekhar's mother explained, “We don't send him [to school]. They've said not to send him. They've said that your kid vomits and there's nobody here to take care of him so you should send an attendant.” Being able to send a full-time attendant is not financially realistic for Shekhar's family, but it is possible for another adult with challenging behaviors, Aakash. Aakash has been able to remain at his school solely because of the full-time attendant who accompanies him; otherwise, his father described that “he can hit and he can

throw things and he can scream, when you're going with him on the road, he may misbehave.”

Another common complaint from parents was that there were no suitable places to meet the adults' particular needs, and the places that were a good fit were not close enough. This was also echoed among families who had settled on less-than-ideal settings because they viewed it as preferable to nothing or to hours of travel each day to reach another part of the city. Delhi is not only extremely spread out, but the traffic congestion is often described as the worst in India. Using geomapping, we calculated that adults travel an average of 8 miles to get where they are going each day, and as much as 18 miles—and these are often lengthy, hot and chaotic rides that can take up to two hours when traffic is at its worst. When a parent is already commuting an hour or more to work each way, it is easy to see how the potential benefits of a structured setting are overshadowed by the logistical burden of adding transportation for the adult.

### 3.1. Parent experiences

As noted, more than a third of the adults are home nearly all the time. The use of the PSI-SF allows comparison within the current sample as well as to other studies of parents of disabled children. We found that approximately 70% of both mothers and fathers in this study had overall levels of reported stress that are considered in the clinical range for this measure (for mothers,  $M = 100.7, SD = 20.9$ ; for fathers,  $M = 104.1, SD = 22.2$ ). While similar to another study of parents of autistic children in India (John, 2012), these scores are higher on average than reported in a number of recent studies of parents with autistic children elsewhere (e.g., Watson et al., 2013; Ben-Sasson et al., 2013; Zaidman-Zait et al., 2010). Based on the PSI, therefore, the parent experience may be described for some as moderately to very stressful, and more so than outside India.

We had hypothesized that there would be an association between parents' stress and the amount of time that adults were home, given how commonly parents mentioned their frustration with not having any place for their adult children to go. We did not, however, see any evidence of this for either mothers or fathers. We then looked at stress from the perspective of burden on the parents. In most Indian families, the mother has the major role in taking care of children, and this is equally true for adult children. We knew from the daily routines that mothers spent the most time with the adult (on average, more than four times as much as fathers) but of course, mothers have other responsibilities as well. We thought it might follow that a source of mothers' stress would be related to the challenge of balancing all her responsibilities.

Indeed, in families where the mother was employed outside the home, both mothers' scores ( $t(45) = -2.862, p = .006$ ) and fathers' scores ( $t(35) = -2.509, p = .017$ ) on the PSI-DC subscale were significantly higher than in those where the mother was retired or unemployed. This may be in part because, regardless of the amount of help that is hired, mothers were the primary caregivers for their adult children in almost every family in this study. Since the DC subscale assesses behavioral characteristics of the adults that make adults easy or difficult to manage, one interpretation is when the daily routine of the central caregiver of the family is overtaxed, the parents perceive the adult as significantly more challenging to manage. It is also possible that mothers are more likely to be employed outside the home in circumstances where adults are more difficult to manage – that there is a causal association. Our study design does not provide a way to directly test these, but both processes likely exist.

Yet in spite of high levels of stress as a group, most families we met did not appear to be in a state of crisis; overall, the family

routines were manageable and described as sustainable by most parents. Similar to parents of children with disabilities in the U.S. (Gallimore et al., 1999; Weisner et al., 2005) parent after parent in this project described the way they have adjusted their expectations and their routines around the needs of their adult—in essence, how they accommodate the disability. Sonu, for example, does not do well with visitors in the home, so when someone comes, “we feed him first and then we take him out so that the other people can eat their meal.” Prakash’s father takes his son for a daily drive and to a restaurant, and because Prakash does not handle change in his routine well, he will enter Prakash’s favorite restaurant ahead of time to ensure that his preferred table is available. If it is occupied, he will ask the diners if they will shift to another table. Anmol’s father explained, “If there is a social function in [my wife’s] family, she goes. We can’t go together. If there is a function in my family, I go, but like his mother is rightly saying, we don’t get depressed because what can’t be cured must be endured.” Anmol’s mother shrugged and added, “Seeing a movie alone is very odd, but now we’ve started enjoying it.”

Beyond just adapting, many families identified how the experience of having a child with ASD has shaped not only their lives and routines, but who they fundamentally are as people. With many of these parents close to retirement or already retired, the positive impact of their children is also clearly expressed through their actions, with no less than five families mentioning the desire to start services for others. Varun’s father explained that had his son not been autistic, he “wouldn’t even have been able to be near to such kids,” but that Varun “inspired my life and changed my life” and he now has plans to start a foundation for children with special needs. The mother of Nandita, a 26 year old, perhaps was the most articulate among all the parents, as she described her daughter:

I see her like somebody who had to come in life for me to have a totally different perspective of life. When I think of myself before Nandita and today, I can say that yes, I am a far better person, and she has taught to me a lot of things. I mean it might sound like a cliché, where every parent says that, but the kind of patience, the kind of understanding – now I always try to be in the other person’s shoes. We do have to make adjustments, compromises, things like that. But then, don’t we do that even if we have just typically growing child? Adjustments, compromises? You know making peace with things, it’s so much part of every human being’s life isn’t it?

#### 4. Discussion and summary

Our study combined interviews, observations, assessments and questionnaire data, consistent with a “multiculture, multiage, multimethod science” (Bornstein, 2002, 257). Overall, in contrast to vivid and sometimes visceral reactions to the impact on the family of having a child with autism that have been described elsewhere (e.g., DeGrace, 2004), most families in our study have accommodated and adapted. These are parents who are long past the stage of thinking that their child will outgrow autism, and have come to understand that the doctors’ previous reassurances that “he’ll catch up eventually” and “by 18, he may speak normally” are simply not true. We found that most adults with autism are not hidden; many spend time in their community and attend social events with their family members. Parents who expressed having accepted their children early on were particularly likely to include adults into broader social situations, and the importance of accepting ones’ child was repeated over and over as a key piece of advice parents wanted to share. Moreover, the routines we heard about very much incorporate the adults—if not cater to them. However, the adults in our study have

limited social contacts outside their families, and parents struggle to structure their adults’ days to reduce the amount of time they spend doing nothing. It bears mention that discomfort with adults roaming or doing nothing all day was reported by the parents, not the adults themselves, who generally appeared happy to be left to engage in repetitive or stereotyped behaviors.

Second, we found that higher functioning adults are more likely to have a structured setting and spend time outside the home, but that two other factors also mattered: Parent/adult preferences and adult disruptive behaviors. Some parents have reached a stage at which they are no longer looking for activities for their adult during the day. Another set of adults, however, is unable to attend structured settings because of their challenging behaviors; for these families, parent training specific to adult populations is needed. Such training must focus on how to address habits that may be deeply engrained and may have formed over a decade or more of repetition.

Third, we heard very clearly that there are not enough suitable work and training facilities and centers in Delhi that are easily accessible, even for adults with no disruptive behaviors. Additional structured environments are needed that are appropriate and respect the dignity of the adults they serve by offering meaningful opportunities for growth. Ideally, opportunities for adults to develop their skills should be located throughout urban areas. Some families may still choose for their adults to remain at home, but the decision for many families in the current study was one by default, rather than by design.

Fourth, both parents reported increased stress when mothers are managing both families and work. Many parents feel that someone must be with the adult at all times, and just because parents have adapted doesn’t mean they would not welcome the opportunity to do things differently. There are limited options for respite care in urban India, and the idea appealed to many families who longed for even a short break from their adult children.

##### 4.1. Making it meaningful: local application

Translating findings such as ours into meaningful actions is a challenge that many in psychological anthropology have encountered, and one identified as a key ethical consideration in other fields (Marshall, 2007). This study was conducted under a partnership called RAFIN, a collaboration between US researchers and AFA. A major impetus of the partnership was to conduct research that is not just scientifically useful, but also personally relevant to the participants and more immediately able to shape policy. Because our partner organization was conversant with local needs and practices, they were able to amplify our research findings far beyond what a published journal article could ever do.

This took several forms. A letter after the home visit included a summary of the visit and specific information that the family may have requested, for example, how to talk to their adult about autism, recommendations for improving hygiene, and possible job options. Second, early on in the study, it became clear that many families had not created wills and needed more information on legal guardianship; AFA organized an event with a lawyer to speak on these and related topics, and also created a packet of information. This event also allowed families of adults to meet one another. Subsequently, a series of three lectures was offered on adult-focused topics. Third, the research team used the organization’s free quarterly journal that reaches approximately 3000 families in India (and is available online) as a way to present the findings piece by piece, so they can reach a wide number of families.

These initial steps toward transforming data into practice are important, but our study also has several important limitations. Most significantly, given the incomes of our families, our sample predominantly represents a middle and upper class urban

experience. Adults located in smaller cities and towns may be less likely to have a diagnosis of ASD, would likely have fewer intervention and placement options than did these families, and might be more hidden. What is striking is that in spite of the resources available, families in Delhi report such struggles to identify appropriate care. A second important limitation is that the depth of information we could obtain during our visits to family homes—as lengthy as they were—was limited. While our methodology gave us a far richer picture than interviews in a school or work setting might, it still fell far short of longer-term ethnography.

In conclusion, there are many features of the daily routines of the adults in our study that are repeated in the US and elsewhere. These features were useful for the Delhi families, but many may also have an application in families in other countries, regions, and settings as well: Careful scheduling and sequencing events in the same order each day; the challenge of matching interests and activities to the abilities of the adult; the challenge of finding the right “fit” for not just the adult but the whole family. A hallmark of autism as a disorder is the range of behaviors and variability in functioning, and parents require very different kinds of supports for higher and lower functioning adults. There are opportunities for adults to attend out-of-home programs in New Delhi, but the goodness of fit between these programs and the perceived needs of the adults is variable. Parents who focus on what makes the adult happy, rather than on continuing to cultivate the adult’s experiences or develop new and improved skills, have chosen a goal that may best fit and accommodate their family circumstances, and match with what the adult wants.

The integration of methods in this study provided a picture of the accommodated daily routine, as well as the experiences of parents in “living with” that routine. We heard stories of remarkable resilience, creativity, acceptance and perseverance embedded within the descriptions of the daily routines such that the interviews often moved and inspired us. Parents have a level of acceptance of what had to be let go in order to even have the routine they have crafted, and there is an awareness of the losses required: less time for extended family visits, mothers who are home more than they would have been otherwise, and so forth. Accommodations like these are accepted and necessary in many cases, but they come at a cost. Reducing the costs or adding new alternatives will take our research, and the participation of our partners at AFA, into the topic of regional and national institutional policies in New Delhi and elsewhere in India.

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