

Teaching Children "Survival" Skills for Adulthood A Wake-Up Call for Parents

by Stacy Hultgren

As parents, we notice all the changes our children go through, and how they mature each year. For some with autism, this development may seem very slow, but the appreciation for the growth they achieve may be more intense than for our typical children who do not struggle so hard. Our children WILL one day be adults, and they will depend heavily on the skills they are taught through their younger years to get them through successfully. These skills should not be put off till high school because they cannot be learned in the short span of time before graduation. Parents should, throughout their children's lives, keep the focus on those survival skills that will enable them to live as independently as possible.

We as parents will, one day, be gone and our kids will be left to fend for themselves. The 'big picture' of life as an adult should be the driving force that determines home and school goals. It is easy to become lost among the daily details and difficulties, and we as a society tend to focus only on academics as a way to a better future. But Calculus will not advance a young adult toward employment without the accompanying skills - a teenager who can't fill out a college application is unlikely to be accepted regardless of how much math he had in high school, and a college graduate with a 4.0 average will never get a job if she doesn't know how to use the phone.

I spoke to a mother of a teenager in high school once, who lamented that her child could never attend college despite how bright she is. "After all," she said, "who would get her out of bed in the morning for class? They don't do that sort of thing in college." This mother was in danger of allowing her child to lose access to the experience of college simply because she had never thought to teach her to use an alarm clock (a very learnable skill). Unfortunately, this girl would never make it to work on time either, because she would be unlikely to learn to use one if no one shows her how.

If you do not have a child with an autism spectrum disorder, there is no way to understand the challenges faced to simply get through each day, and our dream is sometimes just to have everything run smoothly for once. These daily crises, decisions to be made for school and home, and balancing the rest of our world - aging parents, divorce and family illness - leaves little energy to think about what skills a child will need five or ten years from now. But that is what we must do or all the efforts made by family, school staff and private professionals will have been of no value.

SCHOOL SKILLS VS. REAL LIFE SKILLS

Kids with ASD learn many useful skills at school; some of those skills apply in most settings, such as asking a question to get

more information, or respecting another person's turn. There is, however, a great deal of emphasis on inclusion, and one of the reasons given for it's value is because it helps them get ready for the "real world". Unfortunately, the fact is that school settings and demands are rarely replicated in real life. *See chart of just a few examples of the differences on the next page.*

Children with ASD require a great deal of repetition to learn a skill, depend upon routines to help them manage the environment, can't transfer what they learn from one place to another, and have trouble with changes in routines or expectations. We spend many hours a day teaching 'school' skills to children so they can participate in activities, and provide them with a structure that supports them in this environment. But in the lifespan of people with ASD their need for these school-related skills are very short-lived. As we see from the chart, many of the skills kids learn no longer apply when they leave school, and when they leave high school the structure we have taught them to function within is taken away. A student who can perform well in school expectations may fail in a work setting because of some simple differences in those expectations. How long would an adult with ASD keep a job if they arrived at work the first day and waited for someone to tell them to begin, publicized a trip to the bathroom, waited for someone to announce the beginning of lunchtime, asked for help opening lunch containers, and waited at the end of the day for someone to tell them to go home?

"SURVIVAL" SKILLS

There are three things that will most likely be the cause of lost jobs or failed college experiences - social skills, level of independence, and behavior. Anyone who has worked in an office or other work environment can describe co-workers (or fellow college students) who were not motivated to succeed, and didn't put much effort into the job demands. While adults can certainly lose their jobs for these reasons, popularity with one's superiors and co-workers is a definite advantage in keeping that job. If an adult with ASD has behavioral issues that alienate them from their co-workers (i.e. nose picking) they will be far more likely to lose that job regardless of how much effort they expend in doing their work tasks. The truth is simple - people don't want to sit next to nose-pickers. American history and advanced physics will not help this individual keep their job or succeed socially with co-workers. Parents and school personnel must make decisions on the adult survival skills that children don't have and that will prevent them from working, supporting themselves as adults, and from participating in their community. Those skills must be a substantial part of the school and home curriculum. Kids with ASD do not generalize skills from setting to setting and remem-

	SCHOOL	ADULT WORLD OF WORK
Arriving	Sit quietly till an adult tells the class what to do and when to start working; work as a group	Get to work independently; greet co-workers briefly before beginning; self-start on individual work at correct time; sometimes self-determine the work load and priority
Work day	If you need help you raise your hand and an adult will come to your desk; you must ask permission to go to the bathroom; when you finish this assignment another will be given to you by the adult; no assisting others with their work is allowed; no talking is allowed while working; there is a set schedule of times and days for specific activities; the class moves as a group quietly in single file to other areas of the building	You may not be sitting at a desk or even in a single location; you may have to wear a uniform; you must self-pace to complete work on time; ask for more when you are done with a task; go to the bathroom independently; go on other errands (i.e. the storeroom for new supplies) without direction; pitch in and help others as needed; may have to determine own routines or suggest ways to complete work more efficiently; help should be sought out privately with the appropriate person in charge; talking to co-workers is allowed when it doesn't interfere with work; work tasks can change from minute to minute dependent upon many factors
Cafeteria	Eat when told; file in, in single file; sit where assigned or with anyone who will sit by you; an adult supervises the room to avoid trouble or offer assistance; you must eat what is available or bring your own lunch	Can sometimes eat at your desk or other locations in the building; can take a walk; can eat anywhere in town that is nearby; can eat alone or with others of your choice; can skip lunch altogether as work demands or by choice; can use lunch time for personal business
Leaving	Wait for the bell; rush to your locker before the bus leaves	There is no bell; don't leave till your work is done or when it is appropriate; might have to use a time card or complete next week's time schedule

ber that, as we saw in the chart above, the appropriate skills used in school are very different from what they will need as an employee. This makes these types of skills much more difficult to teach in a school environment. Schools are strongly urged to add a 'community learning' piece to the high school (and even middle school) curriculum for kids with ASD that will allow the teacher and student to actually leave the school building. Parents and other family members must also take a very active role in teaching these skills to kids with ASD from as early an age as possible. Parents cannot afford the luxury of expecting the school day to be long enough to encompass everything a child with autism needs to learn. These kids need to learn all day, every day (that means weekends, holidays, and evenings too).

DEVELOP A PLAN

Parents should complete the simple checklist on the next pages. How many of these personal skills do you depend upon to get you through your day, and how many can your child do? Obviously, the current age of your child must be considered, not all skills would be appropriate for all ages, but it is a good beginning to understanding the importance of teaching survival skills early. Take note – as you go through the list, try to imagine your child when he is an adult managing the listed situations with the skill level he already has. Unless you make the decision to teach more of these skills now, those are the same skills he/she will have as an adult. He will not learn them on his own.

There is a plan to teaching all skills in general, and they apply to these skills as well. 1) Determine what he/she needs to learn (begin with the checklist, but add whatever you know from experience with your child), 2) Plan the direct teaching (including who would be best to teach it, what time of day), 3) find

a method that will work to practice the skill, 4) get the child's cooperation in learning the skill (a tangible reward for success, or for kids with Asperger's a logical explanation as to why that skill has meaning), and 5) measure how well he/she can do it on their own.

STRAIGHT-TALKING PRINCIPLES FOR PARENTS

It is harder to un-teach a learned behavior than it is to teach it correctly in the first place. A child, for instance, who sneezes in her hand because no one teaches her what to do when she needs to sneeze, is going to have a harder time learning to ask for Kleenex and to blow her nose correctly after doing it this way for years. If there is a skill like this your child doesn't know, teach it now, because if you don't they will teach themselves the wrong way to do it, and that just makes your job harder.

When a child is frustrated with a task, it is not always the best option to modify expectations. ALL kids have trouble learning some things. If the child doesn't succeed in the first two or three tries, it may indicate a need for more repetition, a different mode of teaching, or teaching some necessary foundational skills. It doesn't necessarily mean that the skill is too hard for him/her to learn, or that he will NEVER be able to learn it. When we expect less, we get less. If there is a concern for the child's ability, look first to the teaching method and frequency to figure out if anything needs to be corrected before reducing the demand. If you do reduce it, only reduce it as much as needed, and only temporarily until foundation skills are learned. Don't eliminate learning the skill entirely.

Beware of behavior tolerance. Sometimes parents make allowances for behaviors in very young children because of their age. While this may be understandable, they then continue to

tolerate that behavior because they simply get so used to seeing it they don't notice it anymore. If, for instance, your child self-talks, over the years you are likely to become desensitized to it, and may be unaware that it is very disturbing to others. Your adult child, however, needs to live in a world with others, so what they think is important too. You may choose to accept the shouting behavior when he's nervous, but the police officer at the mall isn't likely to make that same concession. If he hits at the age of 6, imagine what it will feel like when he hits you when he's 16 and six feet tall. Teaching not to hit is easier to manage with a 6-year-old, so why wait till the job gets harder? Always re-think the age-appropriateness of behaviors - they should never stay the same because kids don't stay the same age.

It is painful for parents to see their disabled children struggle, so many 'enable' them. Some of these same 'enabling' parents allow their typical children to fall off bikes, deal with strike-outs at their little league game, cry over lost friendships, and manage punishments at school for cutting class. Getting 'back up on the horse' after a disappointment is what teaches perseverance, determination, that life isn't always fair, and helps develop "character". We learn more from our mistakes than from our successes. Sometimes parents and school staff, with the best of intentions, support the child so much that they are never allowed to make mistakes (especially when a behavioral meltdown is the result when the child encounters difficulty). While support and encouragement are always in order, 'enabling' children by making things easier for them, eliminating the natural consequences, or lowering our expectations is not helpful to any child. They will soon come to depend upon others to make things easy, to come to their rescue, and to make allowances for lack of effort as well as ability. These are not good life lessons for anyone.

Simply learning routines is not enough - kids, especially those with Asperger's, need to understand the logic behind using skills. Many kids with ASD cannot determine the need for skills because of their lack of perspective-taking (seeing something from another person's point of view). In some cases, this may mean being really blunt about the realities of the world. Citing 'good hygiene' as a reason for using deodorant may not be as clear as explaining, "if you don't use deodorant you will smell bad. People don't like to be near people who smell bad." Sometimes parents shy away from being too callous, and don't make things clear enough for a child with ASD. Kids who develop a personal motivation to follow through on social expectations (not just because it is a rule) are more likely to continue using them when there is no supervisory adult monitoring compliance.

Kids with ASD can manipulate parents just like all kids do. Make no mistake, just because kids with ASD may not have the social understanding to manipulate people by means of teasing, sarcasm, veiled insults, etc. doesn't mean they can't make the simple connections between their behavior and your response. If every time you are the phone they start screaming, and you apologize to the caller and get off the phone, *they have your number.* They will cry every time you pick up the phone until you teach them not to, and if you don't teach them they will continue to do it year, after year, after year..... How many friends will you lose for not establishing the 'no talking when mommy is on the phone' rule? Friends' negative reactions may not be because they don't understand the disability; it may be because they are

not seeing anyone in the process of teaching more appropriate behavior. The child depends upon you to teach him - if you do not, it is not his failing; it is yours. What you will have taught him is that if he wants you off the phone, screaming will work. Moreover, he will not know when he is an adult that he can't interrupt his boss on the phone when he wants his attention.

Understand that your child is, or will become, a sexual being, and this needs to be part of the plan for teaching. If you have a problem with this, get over it. He/she is not going to ignore powerful hormones simply because you are embarrassed. Plan for what he/she must know to be safe, and to develop a meaningful relationship even if you think this unlikely to happen. It is not the time to find out you are wrong when a relationship already exists without the benefit of birth control.

Don't relinquish your responsibility to the school to teach her everything she needs to know for the rest of her life. She comes into this world with her parents as her first teachers, just like all babies do. She will continue to learn long after she ages out of the school system. There are 8760 hours in a year, a little over 5000 if you are only counting waking hours. The school district, while having certain responsibilities that are required by law, are often only involved with your child for about 1000 hours a year, and only for about 15-18 years out of a possible lifespan of 70 or 80. The rest of the 4000 hours a year (give or take a few) this child is yours to teach. If you choose not to invest this time, you are doing her a huge disservice. No one expects parents to designate every waking hour to teaching a child with autism, and they should not even attempt to do so since it would be unfair to all other family members. But if you depend upon the school to do all the teaching, the child will learn only a fraction of what she is capable of if you use many of the teachable moments that naturally occur every day. Simple things like making phone calls, going to a restaurant, shaving, swimming in a neighbor's pool, caring for the dog, etc. are ripe ground for teaching survival skills. These types of things happen routinely, but do not happen in the school building.

Survival skills can best be taught by combined efforts of school and family. Both should recognize and be willing to share their own strengths and limitations, so that needed skills are addressed by those best equipped to handle them. The addition of community 'social coaches' for kids transitioning to college or work can be invaluable (transition begins no later than age 16 by law but can, and should, begin earlier for many students), because they can reach settings and work on expectations that teachers and parents do not have access to (i.e. a work place).

If you have not heard it already, please know that in the state of Connecticut your adult child will receive no help from a state agency unless he/she also has mental retardation or a mental illness. The only help currently available is still inadequate at best, and that is through the Bureau of Rehabilitation Services (BRS). BRS provides short-term job finding and coaching services only. What you do, and do not, teach your child will directly affect his or her entire life, and there will be no one to step in later to take up the slack. If you wish to become involved in promoting legislation to provide state-funded services, please call Lois at ASRC 203) 248-5222. ▸

CHECKLIST FOR ADULT "SURVIVAL" SKILLS

Parents should put a checkmark next to the things YOU do on a routine basis (even if not every day) in the first column. Put a checkmark next to things your child can CURRENTLY do without assistance in the second column. Compare the two columns of checkmarks (even if it wouldn't be expected for him/her to have learned these skills at their current age). Then answer the questions following the listing. **Take note: As you go through the list, try to imagine your child when he is an adult managing these situations with the skill level he already has. Unless you make the decision to teach more of these skills now, those are the same skills he/she will have as an adult. He will not learn them on his own.**

Hygiene

- Importance of general cleanliness
- The importance of using deodorant
- How to use deodorant routinely
- How to shave, including how often to shave
- What to do if cut with a razor
- Razor care (proper cleaning, replacing blade, buying the right blades)
- Hair brushing daily
- Cleaning out a hairbrush
- Using a toothbrush and paste daily
- Using floss
- Care of toothbrush (cleaning, replacing)
- Showering (using soap, rinsing)
- Washing ALL body parts
- Hair washing (how often, rinsing, using conditioner if needed)
- Hair cuts - knowing when needed
- Making appointment for haircut
- Getting to appointment
- Menstrual care (for girls)
- Menstrual care in a public bathroom (i.e. tampon vending machines, disposal)
- Buying menstrual products

Medical

- Use Band-aids, clean cuts
- Know when to seek medical attention (i.e. how much bleeding, recognize infection, what types of pain, how high a fever, etc.)
- Know schedule for medical appointments (teeth cleaning 2 X a year, checkup 1 X a year, etc.)
- Make appointment for dentist/doctor
- Arrange schedule and transportation to appointment
- Get refills on medications
- What to do when refill runs out
- How medical insurance works and who his/her insurance company is
- Who to contact for insurance purposes/questions
- Know what the 'co-pay' is, if applicable (and is prepared to pay it)

Using an Alarm Clock

- Remember to turn on at night
- Awakening

- Can set & re-set time (i.e. Daylight Savings, after a power outage)

Phones

- Answer the phone politely
- Take and deliver an accurate message
- Make general calls (order pizza, call a relative)
- Can use caller ID (if appropriate)
- Use a cell phone
- Routinely charge a cell phone battery
- Know how to use a public phone
- Has emergency phone numbers available and also programmed into cell phone (parents work number, neighbor or relative, doctor, etc.)

Clothing - Dressing/Undressing

- Find appropriate wear for the day
- Dress (pants, shirts, skirts, etc.) without help
- Shoes - tying
- Appropriate accessories; choosing/fastening jewelry, matching socks, shoes that match the outfit and activity (i.e. sneakers vs. dress shoes), sweater in cold weather
- Can dress in cold weather wear - coats, hats, gloves
- Eyeglasses/contacts (if worn); how to care for them, store them
- What to do with worn or cleaned clothes (i.e. hang up, put in hamper, fold, etc.)

Clothing - Shopping

- Choose clothes that fit (know own size, try things on)
- Choose clothes that match or that serve a specific purpose (office wear, outdoor wear, etc.)
- Choose shoes that fit (including knowing how to tell if they fit)
- Choose all clothes within a budget
- Know when clothes are worn out and need replacing
- Know what to do with old clothing (charity, disposal)
- Which colors/patterns match
- How to choose eyeglasses for looks and comfort

Caring for Clothes

- Know the difference between dry clean and wash, looking at labels
- Can do laundry in washer/dryer (including cleaning the dryer filter)
- Fold, press, mend (or how to get these services)
- Could use a Laundromat

Food Preparation

- Can get at least 5 different breakfast meals without assistance
- Can get at least 5 different lunch meals without assistance
- Know several dinner recipes and how to cook them without assistance
- Know about general healthy food groups and likes some items in each category
- Can make a shopping list and purchase needed items for meals
- Can purchase items for the home (toilet paper, laundry soap)
- Can wash dishes and clean up (wipe table, put cold food away, etc.)
- Can use a dishwasher (buy correct soap - i.e. not regular dishwashing soap, rinse dishes, load it, etc.)
- Can use a microwave safely
- Can use an oven safely (remember to shut off)
- Can use a stovetop safely (turn off, don't touch hot coil, no hanging sleeves, etc.)
- Can use a toaster/toaster oven safely (empty crumbs, etc.)
- Know what kind of pot or dish to use for particular dishes (i.e. non-metal for microwave)
- Know how to use and clean a variety of products (coffeepot, mixer, blender, etc.)
- Know how to use knives safely (cut and clean)

Finances

- Use a checkbook regularly and appropriately (checks not to exceed amount of account)
- Routinely record checks written
- Use appropriate social skills to converse with teller, bank workers or customers
- Balance the checking statement

- Save part of his/her paycheck each pay period (if possible)
- Can use an ATM card
- Keep account and pin numbers private
- Know about any benefits he/she qualifies for (medical, Medicaid, SSI, 401K, etc.)
- Know what he/she needs to do for up keep of the benefits
- Pay at least one bill that comes in the mail regularly
- Understand the need to pay bills on time, and has the finances available for expected bills
- Understand car upkeep (if they are driving) – get oil changes regularly, how to pump gas, maintain car insurance, etc.
- Use a credit card appropriately (doesn't overspend)
- Know about phone/internet/mail scams, sales pitches, etc. and how to avoid or decline offers
- If renting an apartment or condo (or might in future) know about leases, building rules, condo assoc., etc.

Home Safety

- Shut lights, fans, etc. off when not in the room
- Shut windows on rainy or snowy days
- Know how to regulate heat and air conditioning (if applies)
- Know how to clean up broken glass
- Know how to recognize a minor home emergency (i.e. leak in faucet, clogged toilet, etc.)
- Know how to recognize a major home emergency (i.e. kitchen fire, intruder)
- Know who to call in the event of a home emergency
- Know general fire/flood safety skills (i.e. how to get out, call 911, and 'stop, drop and roll')
- Has an emergency plan (fires, storms)
- Know the concept: amount of heat, water, electricity used determines amount of the bill
- Know to keep doors locked, how to get in if the house is locked or if the automatic garage door doesn't open (if applicable)
- Who to let in the house (or not let in)
- Know not to share information with others about how to get in the house (i.e. where the spare key is kept)
- Use safe Internet practices (i.e. no personal information given out, only email known people, etc.)

Home Cleanliness

- Know how to change sheets and make a bed
- Know how to clean windows, counters, floors, etc.

- Know to clean the old food out of the refrigerator on a regular basis, how to tell when food has gone bad
- Can manage trash including emptying, taking to curbside
- Know when to call a repairman (phone; cable)
- Know how to plunge a toilet

Caring for Pets (if might be a need in adulthood)

- How to choose a pet
- How to feed a pet (schedule, amount, appropriate food, etc.)
- Walk, exercise pet
- Brush, groom, flea control, etc.
- Vet visits, shots
- What NOT to do with a pet (hurt it, ignore it)

Community Safety

- Know about traffic safety (parking lot, cross streets)
- Know how to contact police, fire, community employees, etc. who can help with problems
- Know about sexual safety (good touch-bad touch, facts, slang terms, protection, reporting abuse)

General and Family Responsibilities

- Is respectful to family members (i.e. speak respectfully, remember to say thank you, help out when asked, etc.)
- Buy cards/gifts (even if requires help with money) for birthdays and other holidays
- Can wrap a gift
- Know about holiday rules and traditions (i.e. can pass out candy on Halloween, help with a Christmas tree, religious ceremonies, etc.)
- Is polite and respectful when visiting relatives' homes for family gatherings
- Know when not to disturb people unless an emergency (when others are on the phone, bathroom, tending the baby, etc.)
- Know when to be quiet (i.e. baby sleeping, family member conversing with others, at the movies, etc.)
- Know how to wait (wait for dinner time to eat, wait for a parent to finish what they are doing to get what he/she wants, etc.)
- Keep inappropriate thoughts to self (i.e. saying unkind things, rejecting unwanted gifts, cursing, etc.)
- Is respectful of others' property (doesn't touch others' possessions, is careful with

household items, furniture, etc.)

- Take care of own property (keep game pieces together, put away leisure items, is careful with own room furniture, etc.)
- Help with chores and household duties, willing to assist with seasonal tasks (raking, shoveling, etc.)
- Accepts household limits (snacks, bedtimes, borrowing cars, turning out lights, etc.)
- Know basic computer care (no spilling on keyboard, scan for viruses, regular updates)
- Know how to use simple tools (screw-driver, hammer)

Work Skills

- Is always on time
- Know how and when to call in sick
- Speak respectfully to superiors and co-workers
- Try hard to do his/her best
- Doesn't need constant reminders and redirection
- Organize time and materials without assistance
- Know and can follow office rules and restrictions (i.e. no access to storeroom, coffee break is only 15 minutes, etc.)
- Ask for help appropriately when needed
- Ask for more work when tasks completed
- Finish tasks in a timely manner
- Is able to socialize when needed (when co-workers strike up a conversation)
- Is able to manage an interview – responds well to questions, handshake, etc., speaks politely, is honest, clear about needs and strengths, etc.)
- Accepts correction and criticism
- Dresses appropriately
- Can fill out job applications and other forms
- Has and knows his/her Social Security Number

General Skills

- Keep a schedule - what he needs to do each day, how much time he needs to get there, how to get there, etc.
- Arrange own schedule – arrange transportation ahead of time, write events in day planner or palm pilot, etc.
- Can drive, or use a public bus or subway system (including use schedules and maps, get change, buy tokens, etc.)
- Know an emergency plan for getting home (relative to call, how to call a taxi)
- Know how to ask a question to gain information – i.e. ask bank teller about balance, service desk to return items, etc.)
- Can order food in a restaurant

- Can eat enough foods not to be prohibitive when eating out
- Know how to calculate tips for service
- Know who to tip and who not to tip
- Does not self-stim in public places
- Know when and where it is appropriate to do private things
- Know how to describe a situation (events leading to an emergency, symptoms of sickness)
- Know how to get information from news papers, news shows, radio (movie schedules, storm updates)

QUESTIONS:

1) What is the difference between your list and your child's list? Are the things he/she lacks likely to affect independence at 1) work, 2) home, 3) community (stores, doctors' offices, public bus, family members' homes, etc.)?

2) Has the lack of these skills already been a problem in the past or present?

3) If skills were previously noted to be lacking, was teaching these skills considered? If not, why not? (Be honest - if they weren't taught because you didn't know how, didn't have time, or couldn't deal with it due to other family issues, it's OK to say so. Just be sure you know what the reasons were). Would you make the same decision now?

4) If you had to list items by priority to your child's life, what would the first three be?

5) How do you plan on teaching these skills now? What do YOU need to be able to teach them successfully (i.e. behavioral training, support from school, support from other family members, etc.) and how can you get what you need?

6) Do you know where your child would like to be in five years? Ten years? (Even if children are currently very young, it is still a good idea to think about this) Do you know where you would like them to be?

Revisit this list in a year and see how you made changes to help your child!