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Selling, Sarah
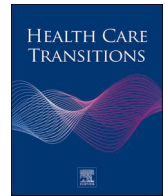
Uba, Allison

et al.

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Framework for developing self-actualization skills in young adults with autism

Megumi J. Okumura [a,*], Sarah Kate Selling [b], Allison Uba [c], Susanne P. Martin-Herz [d], Heidi H. Seretan [e], Lisa Rosene [f], Jacy Cohen [g], Kathleen P. Tebb [h], Roberta S. Rehm [i]

[a] *Divisions of General Pediatrics, General Internal Medicine and Philip R. Lee Institute for Health Policy Studies, 490 Illinois Street, Floor 7, Campus Box 0936, San Francisco, CA 94158, USA*
[b] *School of Medicine, Stanford University, 291 Campus Drive, Stanford, CA 94305, USA*
[c] *Division of General Pediatrics, 3333 California Street STE 245, San Francisco, CA 94122, USA*
[d] *Division of Developmental Medicine, UCSF Box 4054, 1825 Fourth Street, 6th Floor, San Francisco, CA 94143, USA*
[e] *3421 25th Street Apt. 5, San Francisco, CA 94110, USA*
[f] *Regional Center Services, Golden Gate Regional Center, 1355 Market Street, Suite 220, San Francisco, CA 94103, USA*
[g] *Strategic Partnerships, The Arc San Francisco, 1500 Howard Street, San Francisco, CA 94103, USA*
[h] *Department of Pediatrics, Division of Adolescent and Young Adult Medicine, UCSF Benioff Children's Hospital, University of California, San Francisco, Box 0503, LH 245, San Francisco, CA 94143-0503, USA*
[i] *Emeritus, UCSF, School of Nursing, Family Health Care Nursing, 2 Koret Way, N411Y, San Francisco, CA 94143-0606, USA*

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ABSTRACT

Purpose: Young adults with autism spectrum disorder (YAASD) often lack the skills needed for successful adult living and subsequently develop lower quality of life and health in adulthood. Therefore, we developed a framework to support resilience and improve quality of life in YAASD, which will be used to develop a life-skills curriculum for YAASD.
Methods: We conducted a qualitative study of YAASD, parents of YAASD and service providers recruited from agencies that serve YAASD using Grounded Theory. We focused our interviews on supports and skills needed to enhance quality of life in adulthood.
Results: A total of 23 individuals were interviewed. We developed the major theoretical code; "Self-actualization skills in young adults with autism to improve quality of life". This code recognized the neurodiversity of YAASD as well as comorbid intellectual disability and mental health needs, which often were additional barriers to achieving life goals. We identified the need for developing skills to facilitate both independence and greater insight, including self-care, self-advocacy, and social integration. YAASD struggled in developing skills to adapt to the constantly changing environment that neurotypical adults deal with daily. Factors that would facilitate development of self-actualizing skills include resources that promote creating structure in an adult world that can appear unstructured to YAASD.
Conclusions: Self-actualization for adults requires skills for self-care, decision making, and effective communication. Unfortunately, most programs for YAASD emphasize vocational and simple task performance. Our framework facilitates self-actualization skills to enhance health and wellness, potentially reducing barriers to living meaningfully within the community.

1. Background

Young adults with autism spectrum disorder (YAASD) have goals and aspirations for their futures; however, YAASD are often unprepared for the transition to adulthood.[1-3] This has led to poor social, health and mental health outcomes.[4-6] While health and mental health care providers tend to focus transition efforts in health care domains, previous work has illustrated that both supporting a person's ability to live in

their community and ensuring 'life skills' are attained are critical components of maintaining health and wellness.[7,8] Areas of concern in this regard include the transition to independent living, continued learning, and vocational attainment or structured adult activities after exiting school-based programming at age 22, all of which are critical components of independent living.[9] As YAASD transition out of the academic supports provided by school, many experience a degradation of social skills over time with concurrent disengagement in the work sector and healthcare system.[10–12] YAASD require continuous and ongoing skill development in order to maximize their potential and integrate into mainstream activities; however, there are few effective services to meet the needs of YAASD.[13] While healthcare systems try to support YAASD with behavioral and mental health interventions, there are limited interventions that currently support YAASD in their ability to maximize vocational attainment, quality of life, health and mental health, especially as they transfer out of more supportive pediatric programs.[14,15]

Lack of appropriate supports has led to poor rates of educational and vocational success, poor social integration, and poor health outcomes among YAASD.[12] Using a resilience-based framework is a promising strategy for interventions to improve the successful transition of YAASD.[16] The goal of a resilience framework is to establish and build a young adult's protective factors, which include caring relationships, realistic expectations, problem-solving skills, and opportunities for participation and meaningful contribution. These, in turn, contribute to the development of personal strengths, including (but not limited to) a sense of purpose, autonomy, and social competence. These strengths are the foundation of resilience and fundamental to positive long-term educational, social, and health outcomes. Unfortunately, little research exists on building resilience for YAASD.[17]

In order to generate an intervention that will address skills and resiliency in YAASD, we undertook a qualitative study of YAASD, parents of YAASD, and service providers of YAASD to develop a novel framework to guide our approach to improving life skills in YAASD toward the goal of improved quality of life. The goal of this framework is to generate a community-based intervention that would facilitate YAASD self-care, self-advocacy and resiliency within the community. YAASD would then have improved access to physical and mental health care, which would then lead to improvements in quality of life and health.

2. Methods

2.1. Participants and recruitment

We purposively sampled YAASD (ages 18–26), their parents, and individuals who work with YAASD who have exited the secondary education system (clinicians, teachers, case managers/social workers, community service providers). YAASD and parents of YAASD were recruited from local agencies that serve YAASD. We reached these participants online using list serves and in-person at autism-focused community events, as well as through snowball sampling from key informants. For professionals, we recruited from various community, local and state agencies, as well as autism-specific groups located in the greater San Francisco Bay Area. Individuals were interviewed between 8/1/2018–12/15/2018. Young adults represented a range of functional abilities related to autism with moderate to high support needs. We excluded those who were non-verbal or did not speak English.

2.2. Data collection

We used ethnographic methods of interviewing and field note generation for an in-depth examination of the experiences of YAASD as they transitioned out of their child-based programs (school, health care, insurance) and entered community-based services.[18] Interviews were performed either by phone or at a location that was acceptable to the participant(s). Participants were interviewed in person except for two

parent interviews and one provider interview. All interviews were conducted by one member of the study team [SS]. Most interviews were conducted individually with the participant; however, in two cases, the young adults preferred to be interviewed together with their parent(s). Participants were compensated with $25 for their time. YAASD and parent/provider interviews ranged from 30–45 min and 60–90 min in length, respectively. Audio recordings were then transcribed and checked for accuracy, and field notes written. Human Subjects approval for this study was attained through the UCSF Institutional Review Board.

2.3. Interview guide

Interviews for the study included open-ended questions and semi-structured probes to provide an in-depth look at supports needed for YAASD to attain independence in the community. Two interview guides were generated, one for providers, and one for YAASD and their families (Appendix 1). Our goal was to develop a conceptual framework that could be used to develop a curriculum to enhance quality of life. For example, professionals were asked questions such as "Tell me your experience in trying to prepare your students/clients with autism for adult life?" and parents and youth were asked, "How have you been preparing yourself (your son/daughter) for adult life? Further probes centered on what supports were needed: "What are your experiences with receiving assistance to deal with your (your son/daughter's) autism as they become an adult?" and "How prepared do you feel you are (your son/daughter is) for adulthood?" Additional questions probed use of community and educational resources, potential mechanisms that could provide greater assistance to YAASD, and supports that have been lacking during the transition to adulthood.

2.3.1. Data analysis

We used a grounded theoretical approach to the data analysis.[12,15] Data was uploaded into a qualitative data analysis software program, Dedoose (Los Angeles, CA: SocioCultural Research Consultants, LLC www.dedoose.com), for organization and management. Specific steps in the analysis included: 1) Review of each transcript and construction of a participant summary, 2) Open coding of each transcript to identify salient issues, 3) A second round of focused coding for analysis of major categories built from step 2, 4) Theoretical coding of categories developed in step 3, which conceptualized the association of basic social processes affecting barriers and facilitators to care during transition, and explaining both positive and negative outcomes of the transition process described by participants,[18] and 5) A situational analysis to generate a project map based on the interview data.[19] The transcripts were open coded by the study investigators [SS, AU and MO] with each code reviewed by the study team [SS, AU, MO and RR] for agreement of interpretation. After early analyses were conducted, preliminary results and a draft of the situational analysis diagram were shared and discussed with subsequent informants during their interviews to gain iterative feedback to the study and analysis. After development of the theoretical coding and conceptual framework, results were discussed with a group of stakeholders (social workers, educators, clinicians) and researchers with expertise in autism in early adulthood. Using our project map, we then integrated our framework into preexisting life skills and resiliency development frameworks for persons with autism. This framework was then vetted again with our stakeholders to generate a broader autism-specific conceptual framework (see Fig. 1).[19,20]

3. Results

We interviewed a total of 23 persons in order to reach thematic saturation. The demographic profile of participants can be found in Table 1. Two youth interviews were performed with parents present. In our analysis, we developed a theoretical code "Self-actualization in the context of neurodiversity in young adults with autism". Below we discuss the unique categories that led to the development of the
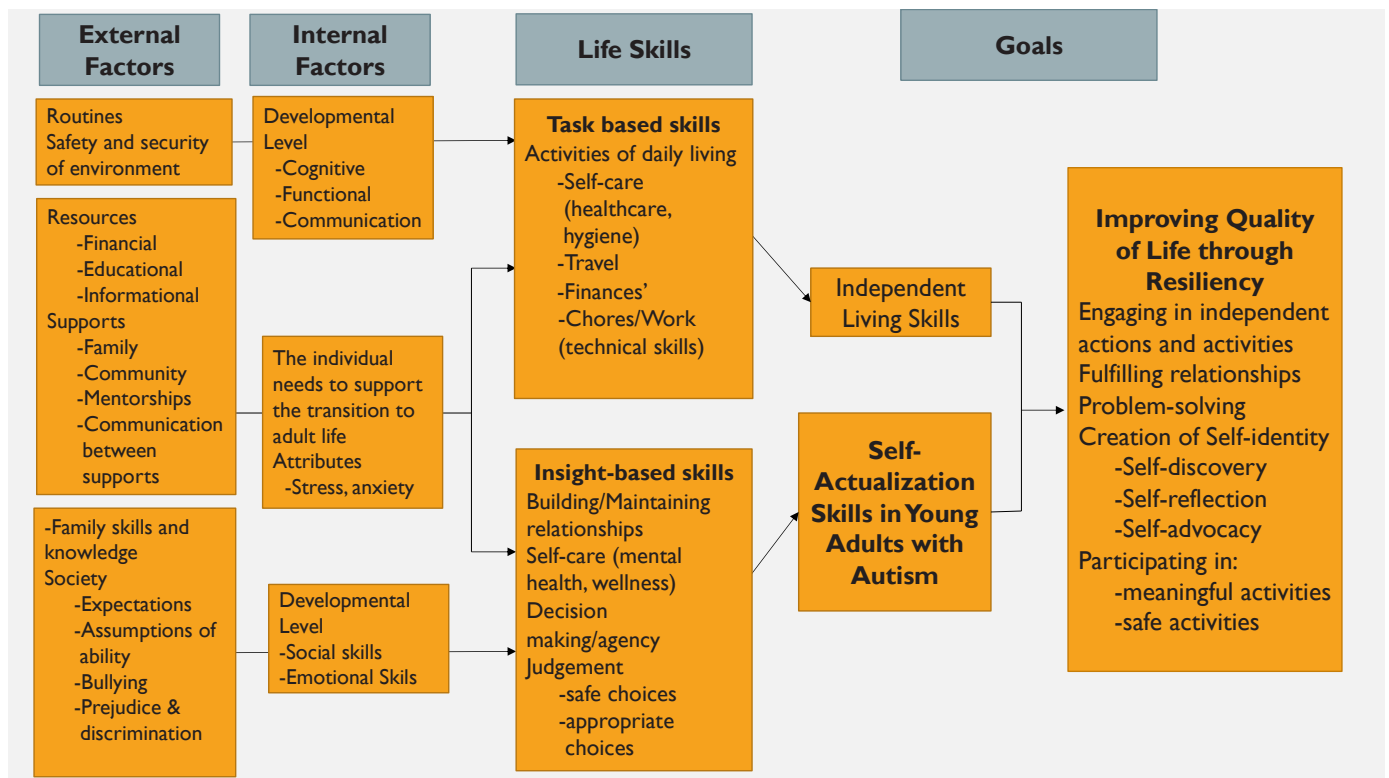
Fig. 1. Fig. 1: Framework to Improve Life Skills in YAASD.

Table 1
Participant demographics.

Table 1. Demographics	n (%)
	Total participants = 23
Female %	13 (57)
Age (mean or range)	
Young adult range (n = 4)	21–24
Providers mean age (n = 4)	42.5
Background	
Youth with Autism	4 (17)
Parent	9 (39)
Community Agency/Providers	10 (43)
Ethnicity	
White	15 (65)
Asian	3 (13)
Hispanic	5 (22)
Black	0 (0)

theoretical code. Specifically, we developed five major categories that were unique to YAASD: Autism Specific Needs, Activities of Daily Living, Social Skills, Resources and Supports, and Transition-Specific Issues. Additional supporting quotes for each category are found in Table 2.

3.1. Autism-specific needs and mental health needs of YAASD

This category focuses on areas that YAASD, families, and providers pointed out as key to develop in order to ensure skills are present to promote high quality of life. The issue of balancing the neurodiverse needs for routine and structure with the social skills and empathy required to function as an adult in the neurotypical community was described by interviewees. This included overcoming the unpredictability of adult life, neurodevelopmental accommodation needs in an "adult-world" environment, the need for social belonging and relationship with peers, the need to receive empathy and recognition of a YAASD's needs and goals, and effective communication of these needs

and goals in order to successfully adapt to the "adult world" environment (Table 2). Adapting to neurodiverse needs and the spectrum of disability was brought up frequently by participants. Addressing the comorbid mental health needs of individuals with autism was raised as a critical component of any support for YAASD.

> *"I think for him his anxiety, working with his anxiety, so that should something happen unexpectedly that it doesn't make him as anxious as it does because it could happen at work, it can happen at any time so working on those skills." (Parent 02)*

> *"I'm working with my therapist about this, is not what I'm about to describe to you, isn't quite post-traumatic stress disorder, but it's on that realm…. What my goal is eventually is that I'll be okay with my past, I'll be able to let it go. My parents and I will be on good terms. I'll be living in [a place] with [my girlfriend], I'll have a fulltime job. We will be happy, and be looking towards things like marriage and stuff." (YAASD 04)*

The need for routine and stability was a frequently mentioned autism-specific subcategory. Participants emphasized the need to deal with real life issues and assist them in the development of skills to cope with the need for "structure in an unstructured adult world". Lacking resilience in adapting to the change from one setting to another, or one provider to another, or one individual activity to another activity was quite challenging for the young adults interviewed. Family members and community providers also echoed this observation, and noted that these challenges were problematic, especially when change occurred quickly or at the last minute. Changing expectations and roles was not something that YAASD were prepared for and they often had difficulty adjusting. One participant commented,

> *"Well, one of the most unexpected things is that I'm having a really hard time with [at work is] doing one thing for eight hours a day, because in school you do have different classes with different activities …. And when you're in college I could tell you in three months on this day, at this time I will be doing this class and I don't have that. It's kind of both monotonous but also unstructured and unexpected at the same time, because I don't*

Table 2

Additional results: categories, sub-categories and participant quotes.

Table 2. Categories and sub-categories descriptions.	Associated quotes*
Autism specific needs	
Structure in an unstructured adult world: need for structure and routine.	"I think [what] had helped people with autism.they had a very routine. predictable schedule When they are coming to a community based program, there are always different elements.in the picture, such as you go to take a bus somewhere and the bus doesn't show up or the bus breaks down.all the different sort of regular unpredictable things that happen day to day. are introduced with needing to learn to be flexible, which is hard for a lot of people with autism right? I mean, life is full of changes. (Provider 08) "He's very schedule oriented. So, I think a part time job, would help him along those lines, keep a schedule and keep his focus on, even meeting people and being out in the community." (Parent 05)
Need for adaptations (e.g. aids/guides/time) to accommodate neurodevelopmental needs (related to school learning)	"Visually. He really needs to look at stuff in order to learn. It's hard for him to just conceptualize things, all things should be like in pictures or words or something that he can kind of look at and repeat and a kind of study" (Parent 05) "The way [he] learns the very best is through video and he has always been able to memorize video.if he had grown up in a time where of YouTube or video instruction, I think he could have learned more. " (Parent 09) In terms of teach[ing] him a curriculum., it was always very visual and very hands on and involved, We were always actively doing something in the class. (Parent 02) "[He] is very schedule oriented. So, once getting into a new schedule that's, you know, it takes a little bit of time and adjustment. Once he gets that down and he has that in front of him, he's pretty good about it." (Parent 05) "A lecture that's just to everybody all at once is not super helpful.I sort of work at a different pace than most students do. Sometimes I'm much faster and sometimes I'm much slower.having a teacher that can recognize that and work with it was useful and not all of my professors did do that, but some of them did. (YAASD 02)
Sense of belonging and developing relationships (related to social skills)	"We didn't highlight relationships,. that's very important because after high school, I think you feel alone a lot of times and you're trying to reach out and there's nobody there and that's the hard part." (Parent 02) "But he desperately wants to participate and he told me once, he said, "I want – I just don't want to be left out." So, and I think we all can identify with that." (Parent 09)
Receiving and being empathetic	"[T]hey think the world. revolves around them and. their need is the most pressing need in the moment and they cannot see the fact that maybe you're busy …there seems to be a lack of understanding of how they affect others. (Provider 07)

Table 2 (*continued*)

Table 2. Categories and sub-categories descriptions.	Associated quotes*
Self-realization/recognition of individual needs	"You ask them questions. and they'll just be like, "Oh, I don't know or I don't know or I'm not good at anything," and it's because people haven't been trying to get to this information with If I don't know what you like to do, if you can't tell me what your hobbies are, how can I help you get a job? I'll end up putting you in something you're going to hate. (Provider 07) I worked in an office and that wasn't my thing. [I was] just stacking papers and printing all the stuff. (YAASD 03) ".the biggest goal is to just think of the job that I want to do as a big job, you know, how those kids would say "I want to be a firefighter", "I want to be a police officer". So, I'm working on that right now." (YAASD 03)
Communication of individual needs	"I had hoped that maybe we could set up some kind of business to employ him. – we have a place out in the country and we thought this is great. He just said, "You're not going to like this, but I don't want to live there.". He made the right decision for himself. That would have been the wrong decision if we had forced him to do that. So, I'm very glad that we listened to him. " (Parent 09) " [Young adult] will have dinner and. he'll say., "Pork." And we're still of a mindset where, "Oh my God, he spoke, he used the word, he asked for something, absolutely [Young adult]." But we're trying to retrain ourselves, "Whole sentence please," because he can come up with the whole sentence… We've had to kind of change our approach to what he has to do to get ready. A one-word request? We're thrilled with. The world outside? They want a whole sentence." (Parent 07)
Activities of daily living: cooking, home, taking care of oneself, bathing, grooming, budgeting, finances, traveling independently and safety	
Incremental mastery of skills and knowledge	"What [transition teacher] was able to do was to then keep moving the goal posts. So, those very inflexible guys have learned a lot of flexibility throughout that time.there was one client who had pushed instructors once down the stairs because the instructors didn't know how to talk to him and he didn't know how to express his emotions and how he was feeling and he didn't have strategies and they now have strategies for when they're stressed." (Parent 08) "So if he's doing a multi-process something in the kitchen, he wants to start and finish each assignment. If we're cooking together., he'll want to start and finish each piece of it, whereas I'm still untrained because I'll still say, "Oh and when you finish that would you—", you know, "No!"" (Parent 9) "Kind of realistic goal setting for them instead of like, "I'm going to have a job tomorrow," and realize that it's going to – it might take a while and you need to take steps to get there." (Provider 05)

Table 2 (*continued*)

Table 2. Categories and sub-categories descriptions.	Associated quotes*
Learning and building skills through routine activities	"[C]reating more opportunities for them to generalize skills outside of our program day.but finding ways to really have them practicing skills kind of across all the settings.[I]f their job is that they're folding laundry and cleaning gym equipment because that's the great job skill to have, but they're not necessarily working on all of those soft skills or communication skills in that job setting" (Provider 09) "I have a pretty set up schedule for each of them in each morning when they arrive over here. That's the key to success because they know as soon as they arrive.the schedule is in there, and the schedule is set up according with their activities. then they start doing their activities independently." (Provider 03)
Safety	"[H]e loves to wear camouflage and I hate it. I explained to him why people might have a negative reaction to a big guy with a big beard wearing camouflage and he just says, "Don't be ridiculous, Mom." [H]e can't get. others' perception of him.I would say his autism is a barrier to him and the social understanding of his autism is a barrier to him of other people.(Parent 9)
Social skills: interpersonal communication of youth, flexibility, conversation, neurotypical vs autism, making friends	
Maintaining friendships/relationships	"[W]e have got to teach kids that it's okay to disappoint their parents. and that their parents still love them and it's going to be okay because I don't see that, I see a lot of [persons with autism] following mom and dad" (Provider 07) "So, saying goodbye to a set of peers that they're familiar with and going to a program where there's less familiar people I know is really daunting for a lot of our folks…And so when somebody departs a program, they – our ability to maintain social relationships is where – it's easier, right?" (Provider 06)
Managing social comfort zones, and communication	"It's been kind of an uphill battle. [For my] first job when – [I] kind of got put into a job that I wasn't really ready for. There were different [social] dynamics. I didn't really understand if you worked there for a long time you could swear, but if you were an intern you couldn't swear. I need my space when I work. So, when I was doing my work.this lass is following me around and I said rudely, stupidly I got angry and said, "Could you please back off? I need my space. I can figure this out on my own." And I got fired. So, then my dad had to quit his job to help me" (YAASD 04) "I think the biggest thing is consent. Just kind of the whole concept of it can be difficult for people to grasp. And sometimes they understand that with themselves like, "Oh I don't want you to touch me, why are you touching me?" but it's really hard for them to accept that from someone else, "Why am I not allowed to do this?". Teaching

Table 2 (*continued*)

Table 2. Categories and sub-categories descriptions.	Associated quotes*
	people that.it goes both ways. (Provider 05)
Self-advocacy	"They don't know appropriate advocacy, they either don't say anything at all or just use their eyes to plead with you, or go to anger., [YAASD need to experience] the dignity of risk and people need to be able to go out and try and fail and do all these things. not like the, "hi, how are you," type of communication but really like "I feel" language –this kind of language it's very-very difficult with this population." (Provider 07) "These kids are trying to create a life and identity for themselves outside of their parents and so I think that the more important parts would be again how to stand up for yourself even though it doesn't feel comfortable." (Provider 07) "He's maybe a little frustrated or a little depressed, he's lost a lot of jobs and stuff and he's afraid to try things I think because he's – because he hasn't succeeded, at some of the things that he's tried." (Parent 04)
Resources and supports	
Family involvement	"Think in order to be successful, it's important to get information [from] all areas, the whole support team and make sure, they [parents/caregivers] are not too worried about telling us the truth about the person. A lot of times they withhold information that makes it even worse. I think it's the honest communication between all parties helps really helps with the success of the person transitioning out." (Provider 02) "I see his mom like, "Oh, he can stock shelves, he would be so great at that right there at The Grocery Outlet" like literally.you see his face, just drop. I'm. showing parents like their children are capable of a lot more than maybe they even thought they were, – and parents are so well intentioned and they just want their kids to be safe. But you end up getting. learned helplessness". (Provider 07)
Community resources and supports	Well, [my professor] knows the industry really well and he knows San Francisco specifically. And he knows me from working with me for four years, and so he was just able to give really specific advice and he cares a lot about what – [and] how I'm doing and what is happening to me in the future. (YAASD 02) ". Four years [ago] on any one day, 33 % of the kids were not in the classroom…. We tried to get to some of that travel training, having him take the Fillmore Street bus home. So, the transition was better and the reason it was better is that the teacher was better and it was in fact in a more appropriate community. (Parent 08) " When he was in a school system, you could throw an IEP.it would be a legal document that would conform to some type of goal setting and laying out some type of behavior analysis or some type of a – of a tool.to try and correct the

Table 2 (*continued*)

Table 2. Categories and sub-categories descriptions.	Associated quotes*
	behavior.[Now] he's kind of stuck between a rock and hard place.He's either a full adult capable of signing contracts and being a daily person or he's going to be part of the criminal justice system. There's no in between. (Parent 01)
Lack of physical/tangible/fundable resources	"Somebody becomes 22-years old and after they'd been in school and they've had all these supports, often one-on-one funding for an aide, all of the sudden they are an adult and they're just dropped into a program and a lot of times the families think, it's all of the sudden they're like [in] a one to six ratio of staff to participants and families like, oh, they're so used to having so many more services through the school system. So, that's been more – I guess that's one of the challenges" (Provider 01)
	" One of the problems is there is a shortage of adult programming, you know, they're getting really impacted, they are too full, a lot of them and for the adult programs hanging on to staff because of the pay. I have to put students on lists, waiting list way ahead, like a year ahead. (Provider 08)
Parent/Staff knowledge of autism-specific needs and individual needs	"If they have people at the school that are familiar with autism, that would be there to support the parents and help the parents to understand how to help their children move from one place to another or to go forward because I'm frustrated a lot.because I don't know how to get him to do the things he needs to do" (Parent 04)
	"I think for him, working with his anxiety, so that should something happen unexpectedly it doesn't make him as anxious as it does because it could happen at work, it can happen at any time so working on those skills.so that it doesn't interfere with his workability. (Parent 02)
	When it comes to autism spectrum disorder, it seems like there's a lot of room for improvement to just being accepting in general. A lot of tech companies are taking people that are within the spectrum because they've seen the value and they see how much it adds to them.We just need to have the appropriate onboarding kind of training, maintenance long-term and having maybe key support people that are assigned to these new employees that can help them through the eyes of not regular HR and onboarding, but helping these particular patients be successful. (Provider 10)
Limited time and understanding of timelines	"To do this correctly, there needs to be meetings happening where the school district and the transitional age program [meet] with the adult program then meet with the families and we're all doing this and we're not starting it 30 days before [YAASD] leave, we are starting this the year before. Parents don't know what happens next, right, they don't have this plan, they don't have this continuous source of information coming to them" (Provider

Table 2 (*continued*)

Table 2. Categories and sub-categories descriptions.	Associated quotes*
	07)
	"I think a lot of times, you know, through nobody's fault but it just gets done last minute and, you know, and that can be really difficult for somebody with autism." (Provider 04)
	"I think longer lead times are really crucial and more familiarity with everything that's out there because there's a lot of stuff that's out there. There's stuff that you just don't know about. We find out like second or third hand information, people that gather up bits of information, but there's no one place where you find all of it unless you know to ask the right questions. If you don't ask the right questions, they don't give you the answers." (Parent 05)
	"Time management, yeah. And you building in time, not just for the essential things but also for, you know, socializing and that kind of thing., I think of myself as an introvert, but I actually have less energy in a large scale when I'm not doing any socializing then I do when I have things to do. And just like seeking out communities that share your interests and beliefs, you know, because if you have something in common with a group of people it's easier to be with them and building that in as part of your life." (YAASD 02)
Transition specific Issues	
Supporting the transition to adult life	"Just providing support, helping them to set goals. It can be a big transition going from one [school] to the other [program] and it can be difficult for people to understand why they're suddenly not allowed to be back in their old classrooms or interact so much with their old peers and stuff. So, really when they transition it's providing a lot of emotional and social support around that." (Provider 05)
	"Probably to talk to somebody who's been through it and can give us a little bit more perspective or what to expect in the transition. [Transition Teacher] has been really good about it and letting us know what to expect. Maybe from a family's perspective maybe? Somebody who's been through it and somebody who has experience with a child who has gone through the process." (Parent 5)
	"That I've done much better with my job and I learned a lot in school for that. [I learned] job skills." (YAASD 3)
	"Yes, [learning to] communicate to workers [Communicating with co-workers] maybe just a little bit hard." (YAASD 01)
	"How do you present yourself, how are you going to communicate with people, [deal with] unexpected things that might happen. It's just how their beautiful mind engages with their surroundings and having them develop those skills…and giving them the opportunity to succeed versus already setting them up for failure, to put them into a setting and really helping them understand what the skill entails and

Table 2 (*continued*)

Table 2. Categories and sub-categories descriptions.	Associated quotes*
From "child" to "adult" roles and activities	especially what value they're bringing to that skill by having them interact with the world in a different way that we do. (Provider 10)
	"Well, I just think it's a really tough adjustment.It could help if students were prepared for what adult life is like as far as consequences to actions.It's really tough for somebody to make that transition anyways if they've been treated kind of like a child their whole life." (Provider 04)
	"I just think in general, we need to be doing a lot more.Everybody who is involved in this field makes the assumption that, now we finished school, now we'll have transition, have a nice life. It doesn't work that way. I see transition as completely ongoing – you just don't get set for lif – it just keeps going." (Parent 09)
	I mean, in being an adult in general has a lot of benefits as well as challenges for me. I had a hard time at home as a kid because I had less control over my own environment. I'm experimenting and learning what the best thing for me is and there's nobody to judge and say that that's wrong, and so that's great, but figuring out the best way to get to sleep and the best kind of personal routines and stuff like that. But also, it's really easy to forget things that I have to do, like brush my teeth and so I've been figuring out systems of like – I have an alarm that goes off 10 min before I have to leave for work and that's when I brush my teeth every morning and things like that. So, you know, being on my own is both ways (YAASD 02)

YAASD = Young Adult with Autism Spectrum Disorder

* Quotes were edited of extra words for purposes of brevity and clarity and skipped phrases are indicated by ".". Full text of original quotes can be requested from the authors.

know like I'll be sewing, but I don't know exactly what activities I'll be doing or who I'll be doing them with. Every day I find out as it happens." (YAASD 02)

3.2. Activities of daily living

For those with greater intellectual disability, providers and families discussed the need for general task-oriented skills through routine activities. (Table 2). The caregivers and community providers indicated the need for YAASD to gain mastery of independent living tasks such as cooking, cleaning, bathing, and traveling around the community, and the amount invested in focusing on these skills varied based on the severity of the person's autism and intellectual capacity. This focus on task-based learning, especially with those with greater intellectual disability, took precedent over other aspects of life.

"When we had the IEP and you presented your IEP to us and when it was – when you had the goals or renewed the goals, I think the goals were "learning to get around the community safely". There was his last IEP, there was a goal in regards to communication because we had some challenges with that towards the end. What else were some goals? I think they were mainly the preparing him for work, independent work". (Parent 02)

The continued incremental mastery of skills or educational gains by YAASD was highlighted regardless of whether or not there was intellectual disability. Meanwhile, caregivers and providers also indicated that while this was important, it was not enough to support YAASD in society. The current programs lacked focus on social skills, and skills to promote self-growth.

3.3. Social skills

Developing social skills is a well-known challenge within the autism community. The need for ongoing social skills development was such a predominant issue brought up by respondents that it became its own major category rather than a subcategory under autism-specific issues. The need to develop skills for friendships, personal relationships, build rapport with providers and employment-related interaction was of key importance for families and providers as a life skill. In addition, safety and social comfort zones and appropriate/inappropriate communication were key areas that continued to require focus and attention for YAASD, including within online and social media settings. Notably, multiple YAASD felt that social media use was already an area of strength, which contrasted with the perspective of parents and providers, who focused their concerns on security and boundary setting in YAASD.

"What happened to me yesterday is that – and this has only happened a couple of times ever, is that I just – I was hungry but I could not deal with the physical sensation of eating and that was a problem obviously. And I like went to my online communities, I'm just like, "I can't eat right now. I need suggestions." And somebody suggested that I have a sugary drink because that often will make them feel more hungry and that actually worked for me." (YAASD 02)

Parent: Social media, which I'm totally against by the way. We have no computer access for him at home for well-founded reasons. I could write you a book on that one. Just like this, does nobody good, like my daughter doesn't do it. (Parent 06)

Young adult: I use it [social media] to connect from people from a long time ago, that [are with] positive people that I'm friends with. (YAASD 04)

Finally, teaching self-advocacy skills for YAASD was important to ensure YAASD could fully develop next steps for adult-related activities and guidance in developing a safe and fulfilling social sphere. Participants generally said there were few resources available that could foster YAASD social skills that enhance resilience and support a good quality of life. YAASD wanted their own agency in developing relationships and connecting to self-actualize.

3.4. Resources and supports

Having appropriate resources to engage YAASD in a safe environment was identified as a problem for most YAASD, including family support, community resources and having access to appropriate programs with sufficient staffing. For families, this also included time to process this support and for YAASD, additional time was a resource needed for day to day activities. Families and providers noted a need for "adult programs" that were sensitive to the unique needs of persons with autism, such as internship and job opportunities. Respondents noted need for guidance for young adults and families in finding, navigating, and funding such opportunities. Even when resources were available, both family members and providers highlighted the challenges in finding the right fit for the unique and diverse needs of YAASD. In addition, there were long wait times for services. There was significant need for appropriate technologies to support the spectrum of need for individuals with autism to maximize integration within the community.

3.5. Transition-specific issues

All respondents noted that YAASD needed support to move from a "child" level of responsibility to adult level of responsibility. Guidance on the expectations and responsibilities of being an adult, changes in other person's expectations of the YAASD, and ensuring YAASD can meeting expectations in day to day activities was cited across all respondents. At the same time, YAASD reported high levels of stress in meeting the demands of having a job or ensuring engagement in activities (Table 2).

Development of the Theoretical Code: *Self-Actualization Skills in Young Adults with Autism to Improve Quality of Life and Resilience.*

The interviews highlighted that "life skills" to promote quality of life were actually comprised of two distinct areas that accommodate the spectrum of disability found in persons with autism. The first is more task-oriented, or what we would consider activities of daily living (ADLs). ADLs included the ability for someone to wash themselves, dress themselves, feed themselves and maintain the ability to function (work, stay healthy) and navigate within society. The second, equally important but often neglected focus was life skills to be able to self-actualize or "insight" based skills; this includes areas such as building and maintaining relationships, communicating appropriately across personal and professional settings, dealing with conflict, and advocating for themselves. It also included recognizing their own strengths and interests and being able to think proactively about their needs, whether it be establishing and working towards life goals or taking care of personal health, which included safety, health care, and mental health. This also included how to deal with life's stressors in order to meet individual goals, deal with adversity, or demonstrate resilience. YAASD, parents and providers described that self-actualization as part of "life skills" was considered critically important. Self-actualizing life skills were thought to be a missing link to the ability of YAASD to succeed in society. Therefore, the unique theoretical code developed through the interviews was "Self-actualization skills in young adults with autism to improve quality of life and resilience". Unfortunately, opportunities to develop skills around self-actualization or resiliency are typically lacking in school and in adult programs. When asked what kind of "life skills" YAASD might need, one provider concisely summarized this point,

> *"I think a curriculum around that emotional resilience, honesty and advocacy is really important. these kids are trying to create a life and identity for themselves outside of their parents and so I think that the more important parts would be again how to stand up for yourself even though it doesn't feel comfortable, right, and how to appreciate who you are even though other people make you feel uncomfortable about it." (Provider 07)*

3.6. Development of a framework to improve life skills in YAASD

Using the theoretical code, we developed a unique YAASD-specific life skills framework for use in future program development to highlight those insight/resiliency developing skills (Fig. 1). The targets in the framework were generated using the codes identified in this work and from previous life skills and resiliency research [17]. Previous work had specifically focused on external barriers and facilitators encountered by YAASD, along with addressing known developmental barriers that come with autism and a focus on task-based learning. The work from this study added the key domain of "self-actualization" along with factors that support self-actualization such as resiliency.

4. Discussion

Some of our findings reiterate previous work noting the neurodiverse factors and significant comorbidities that come with autism (e.g. developmental delay, anxiety) [6,21]. The YAASD in our study, similar to other YAASD nationally, face numerous challenges to full integration in local communities in terms of vocation, schooling, and activities as YAASD move from a "child oriented' to "adult oriented" roles [22]. While the barriers encountered by YAASD in our study were similar to previous work, our work also highlighted the key need for building self-actualization through resiliency and self-advocacy. Developing self-actualization and resiliency skills is a potential way to improve mental health and overcome challenges experienced by YAASD [16]. Our conceptual model (Fig. 1) adds additional target areas for curriculum and supports to develop life skills and enhance self-actualization, resiliency and ultimately quality of life of YAASD in the YAASD community. The heterogeneity of YAASD is a challenge for many programs and thus, ensuring that the program can adapt to the needs of YAASD across the autism spectrum and for both those with and without intellectual disability or mental health conditions (e.g., anxiety) will help serve a broader range of YAASD in the communities where they reside.

Future work is needed to test integration of self-reflection and resiliency into life skills programs and whether such adaptation maximizes individual potential and improves outcomes for YAASD. [15] The focus of current programs on remedial activities, rather than "insight-based" skills, prevents YAASD from working on tasks that focus on preventive needs such as socialization and self-care, leading to decreased prioritization of health care and mental health needs. In addition, teaching YAASD how to cope with and self-advocate to overcome the lack of understanding by employers and others of the neurodivergent needs of YAASD may also help relieve anxiety in the workplace. [12,16] Meanwhile, YAASD could also use continuous supports to ensure that their mental health and social needs are met. [23] Our work suggests that training YAASD to develop and reflect on realistic personal goals, cultivate adult relationships, learn to advocate for personal needs in a safe way are potential curriculum topics that would benefit YAASD (Fig. 1).

5. Limitations

This is a qualitative study reflecting the experiences of YAASD in the San Francisco Bay Area and may not be generalizable to all young adults with autism. California has specific supports for individuals with autism, which may be lacking in other areas of the country, therefore, our framework could potentially lack domains that were not found to be an issue in our study sample. The study was done in 2018 and thus programs may have changed. Unfortunately, the issues faced with clients with our community partners in 2018 persist today and our findings remain unique as to compared to recent published work [16,22] Despite these limitations, the characteristic challenges of having autism are likely not regional and, thus, this study still highlights important concepts to meeting the needs of YAASD in their community. While we had a Latino and Asian representation, our sample did not have persons of African ancestry, which may limit perspectives on potential disparities in autism support. Lastly, obtaining and coordinating services for YAASD is a problem cited nationally, especially with the diverse needs of this population. This may be even worse for those YAASD who live in states that have little or no funding for adults with autism.

6. Conclusions

Overall, our findings and framework provide target areas for community support program or curriculum development focused on improving YAASD quality of life. This study brings to light the need for additional "adult life" supports which focus on skill development for self-actualization and resiliency. Although self-actualization skills are likely more challenging to teach and support; without self-guided goals, the ability for YAASD to maintain their health and wellness becomes compromised. Finally, improving self-actualization skills would better allow YAASD to contribute their unique strengths and neurodiversity to our communities, health care systems, and society at large.

Ethics statement

All research performed by investigators in this work has fulfilled all relevant ethical guidelines including statements of approval/consent. Our work included human subjects, and thus, this study was approved by the University of California, San Francisco Committee on Human Research Subjects, our Institutional Review Board. All research abided by the rules set forth by the Declaration of Helsinki. All participants gave informed consent prior to the study initiation. No AI systems were used in the generation of this manuscript. The authors have no conflicts of interest to report.

Author contributions

All authors contributed to the study conception, design and review of data and editing of the manuscript. Material preparation, data collection and analysis were performed by Megumi Okumura, Sarah Selling, Roberta Rehm and Allison Uba. The first draft of the manuscript was written by Megumi Okumura and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Martin-Herz Susanne P: Conceptualization, Formal analysis, Investigation, Methodology, Writing – original draft, Writing – review & editing. **Seretan Heidi:** Conceptualization, Visualization, Writing – original draft, Writing – review & editing. **Rosene Lisa:** Conceptualization, Formal analysis, Validation, Writing – original draft, Writing – review & editing. **Cohen Jacy:** Conceptualization, Formal analysis, Investigation, Writing – original draft, Writing – review & editing. **Tebb Kathleen:** Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Visualization, Writing – original draft, Writing – review & editing. **Rehm Roberta S:** Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Validation, Visualization, Writing – original draft, Writing – review & editing. **Okumura Megumi J:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Software, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing. **Selling Sarah Kate:** Data curation, Formal analysis, Writing – original draft, Writing – review & editing. **Uba Allison:** Formal analysis, Investigation, Validation, Visualization, Writing – original draft, Writing – review & editing.

Declaration of Competing Interest

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Data Availability

Data will be made available on request.

Appendix 1: Interview guides

Interview guide for Agency Staff and Educators & Other Service Providers

Questions	Prompts
In what context do you personally work with young adults with autism?	• How long have you worked with clients? • What do you do with clients? • What is your role in transition-aged young adults with autism? • Are there other agencies that you work with?
Tell me your experience in trying to help young adults with autism transition to adult life?	• What are things that have helped you or your clients with autism? • What are things you think would help you or your agency/practice to assist in preparing for the transition from school to adult life? • What has your interaction with community organizations or other services been like? • What do you need most to support young adults with autism transitioning out of school?
What do you think about the state of transition preparedness of the young adults with whom you work?	• What skill sets are they well prepared in? • What are they missing? • What are the barriers to meeting your client/students' needs? • What are the facilitators to meeting their needs?

Interview guide for Young Adults with Autism and Families

Questions	Prompts
What has your (your son/daughter's) experience been in leaving the school system?	• What unexpected changes/differences did you experience in the transition? o What were you prepared for? o What were you not prepared for? • What are some of your and your family's challenges in transitioning to adulthood? • What are things that you think would help you or your family in preparing for the transition from school to adult life?

(*continued*)

What were your (your son/daughter's) post-secondary transition goals leaving the school district? (education & training, employment, independent living)	• How were you involved in setting these goals? • Have you been able to achieve those goals? Why or why not? • What are the barriers to reaching those goals? • Have your goals shifted since transferring?
What role did teachers play in your (your son/daughter's) transfer out of school?	• What was a positive experience? • What could have been improved?
How prepared do you (your son/daughter) feel for adulthood?	• What do you think has worked well for you (your son/daughter) in your school-based transition program? • What do you think still needs improvement?
Tell me about your (your son/daughter's) interactions with the teachers and coaches you've worked with.	• How did you (they) learn best in class? • How did they help to meet your (their) needs? • What hinders your ability to have your (their) needs met? • What are current challenges that you (your son/daughter) face in the classroom now?

References

1. Zablotsky B, Rast J, Bramlett MD, Shattuck PT. Health care transition planning among youth with ASD and other mental, behavioral, and developmental disorders. *Matern Child Health J*. 2020;24(6):796–804.
2. Milen MTMRS, Nicholas DB. Examining transitions from youth to adult services for young persons with autism. *Soc Work Health Care*. 2017;56(7):636–648.
3. Kuo AA, Crapnell T, Lau L, Anderson KA, Shattuck P. Stakeholder perspectives on research and practice in autism and transition. *Pediatrics*. 2018;141(Suppl 4): S293–S299.
4. Fortuna RJ, Robinson L, Smith TH, et al. Health conditions and functional status in adults with autism: a cross-sectional evaluation. *J Gen Intern Med*. 2016;31(1): 77–84.
5. Keller R, Chieregato S, Bari S, et al. Autism in adulthood: clinical and demographic characteristics of a cohort of five hundred persons with autism analyzed by a novel multistep network model. *Brain Sci*. 2020;10(7).
6. Roux AM, Shea LL, Steinberg H, et al. Evidence from the Autism Transitions Research Project (2017–2022): capstone review and services research recommendations. *Autism Res*. 2023;16(3):480–496.
7. Okumura MJ, Saunders M, Rehm RS. The role of health advocacy in transitions from pediatric to adult care for children with special health care needs: bridging families, provider and community services. *J Pedia Nurs*. 2015;30(5):714–723.
8. van Schalkwyk GI, Volkmar FR. Autism spectrum disorders: challenges and opportunities for transition to adulthood. *Child Adolesc Psychiatr Clin N Am*. 2017;26 (2):329–339.
9. Berg KA, Ishler KJ, Lytle S, et al. Don't promise something you can't deliver:" caregivers' advice for improving services to adolescents and young adults with autism. *Autism Res Treat*. 2023;2023, 6597554.
10. Anderson C, Butt C. Young adults on the autism spectrum: the struggle for appropriate services. *J Autism Dev Disord*. 2018;48(11):3912–3925.
11. Pezzimenti F., Durrani E., Zheng S., Adams R.E., Bishop S.L., Taylor J.L. Perspectives on Employer-Initiated Terminations Among Young Adults on the Autism Spectrum.

12. Pezzimenti F, Durrani E, Zheng S, Adams RE, Bishop SL, Taylor JL. Perspectives on employer-initiated terminations among young adults on the autism spectrum. *J Autism Dev Disord*. 2023.
13. Monahan J, Freedman B, Pini K, Lloyd R. Autistic input in social skills interventions for young adults: a systematic review of the literature. *Rev J Autism Dev Disord*. 2023; 10(1):1–21.
14. King C, Merrick H, Le Couteur A. How should we support young people with ASD and mental health problems as they navigate the transition to adult life including access to adult healthcare services. *Epidemiol Psychiatr Sci*. 2020;29, e90.
15. Syriopoulou-Delli CK, Sarri K. Vocational rehabilitation of adolescents and young adults with autism spectrum disorder: a review. *Int J Dev Disabil*. 2023:1–20.
16. Ghanouni P, Quirke S. Resilience and coping strategies in adults with autism spectrum disorder. *J Autism Dev Disord*. 2023;53(1):456–467.
17. Elsabbagh M. Linking risk factors and outcomes in autism spectrum disorder: is there evidence for resilience? *Bmj*. 2020;368:l6880.
18. Charmaz K. *Constructing grounded theory*. 2nd ed..,. Thousand Oaks, CA: Sage Publications,; 2013.
19. Clarke A. *Situational analysis: grounded theory after the postmodern turn*. Thousand Oaks, Calif.: Sage Publications,; 2005.
20. Lincoln YS, Guba EG. *Naturalistic inquiry*. Beverly Hills, Calif.: Sage Publications; 1985.
21. Lever AG, Geurts HM. Psychiatric co-occurring symptoms and disorders in young, middle-aged, and older adults with autism spectrum disorder. *J Autism Dev Disord*. 2016;46(6):1916–1930.
22. Lee H, Lee GK, Chun J, Kuo H-J, Curtiss SL, Okyere C. Perspectives of autistic emerging adults, parents, and practitioners on the transition to adulthood. *J Child Fam Stud*. 2023;32(3):938–950.
23. Camm-Crosbie L, Bradley L, Shaw R, Baron-Cohen S, Cassidy S. People like me don't get support': autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism*. 2019;23(6):1431–1441.