

ASD Advisory Committee Adults with ASD Workgroup Meeting

Participants: Jim Adams, Danny Openden, Devin Dale (Jim's assistant at ASU, helped with survey and report) Karla Birkholz; On phone: Denise Resnik, Elanie Estrada

Facilitator: Sharon Flanagan-Hyde

Notes: Mohamed Arif

Note: Next meeting is November 30, 2015, 1:00-3:00 p.m. at Denise Resnik's office, 717 E. Maryland Avenue, Suite 110

Job Survey Draft Report

Devin helped collect and analyze the survey data and comments

Who filled out this survey - 75% participants were filled out by parents, 25% were individuals on the spectrum

Age spread - Half were under 24 years old, half were 25 years and older

Education background – a few are still in high school, 1% dropped out, some were in a vocational program; 13% are college students currently; 13% completed some college courses; 7% completed an associates degree; and 15% completed bachelor's degree; 6% had a master's degree; one individual finished a PhD.

Current job situation- 50% employed; 50% unemployed.

Very small percent are working in center based/sheltered workshop; very small % in group based employment; 10% are working with support; 27% are working without supports (this is good news-they are able to do well on their own); a few % are self employed; 27% unemployed looking for work; 22% unemployed not looking for work- some of them are in school; but 50% are not in school and have given up.

We got a lot of responses of currently what they do-Handful of individuals hold professional jobs; majority have entry level jobs.

Job satisfaction - (this was only for those were employed)-75% rate their job satisfaction as good or higher.

Typical salary - sheltered workshops \$3 /hr; group support \$3/hr; working without supports \$16/hr.

Hours a week they typically work - working about 27 hours per week-which is pretty close to what they would like to work-33 hours per week

The amount of support they receive - they get about \$350/month from Social Security; there was about 20% who did not answer this question.

Commuting - How much times are they spending on commuting – result typical of many people - some 10-20 min; some 20-30; but there are a few commuting 60-90 minutes.

Barriers to employment- 20% don't know what sort of work they want to do; 30% can't find a job to apply for—sadly 55% can't get passed the job interview (the biggest barrier is to get passed the job interviews); 20% can't keep a job once they get it; 10% say job requires too many hours; 25% lack of transportation; 40% state whole bunch of other barriers—they need different types of assistance including job coaches to help them.

Item 14-Challenges-

Findings and keeping a job; After reading all of the comments and categorizing these (Devin helped complete this task) - main challenges people are finding are:

- They are having problems finding and/or getting passed interviews
- Lack of support from current services—they have asked for help but it is not working out
- Need for job training support or work experience—job coaching; developing skills they need for different jobs
- ASD symptoms inhibiting job acquisition—some are physical disabilities, learning disabilities, behavior, anxiety – individuals are very stressed out at work
- Needing someone with an understanding of ASD to work with possible employer – needing someone who understands ASD to help them make the job work within their ability (accommodation)

We put in a few recommendations here and we have a full listing at the end.

1. I think they need a job finder—someone who will find the job and talk to the employer to do a pre-interview to tell them here is what the challenges are for someone who has ASD and also tell them about what their strengths are.
2. Eliminate the gap b/w VR and DDD; some people who are not getting services are being refused by both agencies. You are too high functioning for DDD and too low function for VR.
3. Need for more work experience – many have gone through high school, college but haven't worked.
4. Need accommodations for ASD symptoms- example→ a fixed schedule.

Item 15-Problems of finding and keeping a job

Categories

- Job coaching and training
- More support
- Teaching interviewing skills and application
- Need someone w/ ASD understanding to work with employers

Recommendation:

- Job shadowing-allowing for individuals with ASD to shadow a person at work to know what the job entails-before getting into the job
- Getting training and acquiring/practicing the skills required for the job prior to starting job in order to reduce training on the job
- Allowing coach to work on-site
- Continuing assistance as needed
- Having a job finder - most employers don't know how to interact/manage individuals with ASD- job finder can help market strengths of having an ASD employee
- Portfolio of referrals
- Job buddy- individuals w/ ASD may need more assistance at the job. Job coach cannot be at the workplace everyday to assist the individual. It would be better to have a job buddy that could work in parallel with them in case where there is a problem, they will be there to help them

Items 16- DDD services used

- 65% have not used any DDD services (this is someone what a more high functioning group who have responded); 10% have used center based employment; 12% transition to employment; I don't think these services are well utilized

Item 17-Satsistication

- 2/3 of individuals were satisfied w/ Center based employment - few suggested were made on ways to improve CBE including better work or more work-sometimes individuals run out of work to do-they are sorting pieces and creating "make work" for them; CBE is also viewed as a dead end as supposed to transition to more independent employment; individuals should rotate between jobs b/c that will help

Recommendations

- Having one person find work for the clients to do - they are currently working for about \$3/hour at CBE. If you have 50 clients in sheltered workshop and each client gives \$1 you can hire someone to look for work. If DDD can't pay for it ask each client to use 10% of their paycheck towards a job finder. When my daughter was in the CBE she had no work -it was a waste for a \$5 paycheck every two weeks
- Creating a long term plan for CBE- I think this setting can primarily be used for internships

Overall satisfaction w/ group based employment

- Everyone rates it good or better
- Two suggestions – optional rotation among group based employment opportunities (if you are doing one thing you should rotate to another group based employment activity)
- Teaching DDD support staff how to phase support so people gain more independence overtime

Transition to employment

- Not so good - only 1/3 of individuals rated transition to employment as good or better
- More training for the staff; more learning opportunities; a lot of challenges
- Recommendation-
 - If you can't find employment-you should have the opportunity to do volunteer work or an internship
 - Need for ASD specific training for staff-having 3% of their VR staff and getting them trained in ASD – this is what we did in DDD 15 years ago-few became it worked very well.
 - Employers and employees need a little bit of training on ASD

Employment support aids

- Very well rated-good or excellent

Question: do you have any thoughts on why people are not using employment support aid services?

- Honestly, no. We are trying to gather information and perhaps training staff on this employment opportunity. We don't know what is preventing individuals from participating...is it fear? Or is not being delivered during FSA? We have acknowledged this problem and we are looking at ways to get these numbers up.

I think we should make a recommendation to have employment support aid to be used more.

Individual support employment

Mixed reviews - half rated as good or better - but there are a lot challenges as well

Challenges-better training for staff- not having individuals at the employment facility that understand ASD; not having enough support at work; more job opportunities.

In general- underemployment-most individuals are in entry level positions- we need to have higher expectation-a person w/ Bachelor's degree is offered a job washing dishes

Recommendation-better job support; paying individuals an hourly rate; also find a family perspective we are clueless on what is going on at work-the job buddy can spend 5 minutes a week texting to the family how the job week was overall-this would be huge- I as a parent would be so thrilled to hear that kind of feedback

I think the expectation for this programs are low b/c our expectation for the people we are hire for this job is low.

You want to have someone who knows what they are doing-we need that for this program-also training individuals for ASD could help

I was surprised that individuals were able to get some services from VR

Work exploration was 20%; work training 10%; psyc evals 20%; vocational evals 30%; functional capacity eval 15%; assisting technology a few

Question 28-how did the services help

10% of the cases led to a job; 10% of cases somewhat helped find a job; 80% of the time services did not help. They are getting services but they are not the right ones.

For those who did find a job-they were satisfied but they are a few

Item 30

- The responses-2/3 are unhappy with the job exploration; they didn't like the jobs that they were offered; the jobs were not a good match for them;
- Recommendation-instead of using people who know nothing about ASD to do these services, I would rather hire parents, special ed aids, people who have experienced doing this-they could work as a possible job coach- I have heard of stories where parents have said that they did the job coaching, prepared their child for the interview. Their child got the job.
- Second the issue of job shadowing-the job is not a right fit-what this job entails- go spend a day find what this work involves-
- Minimizing unemployment-it means giving a person a simple job-a person had told a parent that the only job their child can do is pick up dog poop-that is not something that you want to hear.

Recommendation-Adjusted training; there were some issues with respect; and getting a job buddy for people

Do you think the responders understood difference between the different services? Because I couldn't tell the difference between work exploration and work adjustment training.

I think some of them knew and many of them don't. We did include a brief explanation of what each service was..but yes clearly some responses were in the wrong category. I think there was some confusion about those two particularly.

The child has gone through years of psyc evals and they did not need it; the parents gets a psyc eval but it doesn't make an impact/is not used to place individual in desired work.

Vocational eval-response was not good-people have problems with bad placement-follow-generally not listened do-someone says they want to be a dancer but the job placement program says no b/c you can't find a job doing that; better job placement process (faster process); staff did not understand ASD; and variety of other issues.

Good insight- individual w/ ASD response talked about how other people in the work place socialize and they bad mouth their boss and other employees-and how they complain about this-this gives an insight on to their whole perspective on how hard it is to deal w/ social communication at work.

Recommendations-get individuals opportunities (internships) while in high school-don't wait until they graduate; a lot of internships did not lead to jobs b/c the volunteer work was make-work often not designed for a permanent position. So being careful that volunteer and internship may not likely lead to a job.

Functional capacity eval - generally well rated-no real recommendation there

Supportive education- for the 10% of individuals who have done it-loved it-they said it was very helpful-but a few had problems navigating the system.

Assistance w/ technology- only a few used this; and they were pleased with it.

Last page for if you want to know how many people have answered the questions - the general response rates were high-we used display logic so that people who were unemployed did not have to answer questions about their job.

The recommendations is where I would like to focus on - I would love if people could help with trimming some of the items-maybe after the meeting

Devin organized the recommendations under general recommendations, service specific recommendations, ASD knowledge recommendations and job coaching and job buddies.

Thank you for doing this survey-this is a great-this level of analysis requires a lot of work so thank you.

In general, do most of these recommendations seem on board to you?

Yes definitely. This great. It's been very helpful, thank you.

Do you think that a job buddy seems feasible-using /hiring someone at the workplace as a job buddy? Either the employer can say 10% of your job is to help this person. Or DDD can hire this person and ask if they can write a weekly report on the individual, be there to help them if they need support or have a meltdown. For someone individuals they need support for life-if you are blind you need that guide dog for life. if you have ASD and have a lack of social understanding you can use a job buddy to be there when you run into a situation. They could be there to help long term.

I like the idea.

Yes, often in this work what I like to do is often find if anything like that currently exist. It's not just for individuals w/ ASD is there a job buddy-a company or university that have already doing things for onboarding talent?

I think there are in some cases when you hire someone new you might have someone to help you out on the first few days on the job. It is usually a short term. I think, yes, there is a short term need..but there is also the longer term social interaction-your job skills get you hired-but the lack of social skills gets you fired.

I like the idea of thinking about the context of natural support. Especially if we think about it, we don't have the capacity to hire people do the work to support individuals on the job given the high turnover of those positions. I like the idea of thinking about what DDD can provide for the employer for a portion of that individuals time that is spent-I think that is a more sustainable solution from a financial perspective and from a keeping your jobs perspective. The employers being consistently incentivized for having someone there...it will take less time from an agency perspective to train individuals to consult with them.

I am not envisioning hiring a new person. I am just saying that 5-10% of your job for an individual working there should be to assist the person w/ ASD..

Yes I understood it as that way.

I think you make a good point. Instead of DDD hiring the individual at the workplace, arrangements can be made directly b/w DDD and the employer. That might be smoother. I believe there are financial incentives for companies to hire people w/ disabilities, but I am not sure-it's not my area of expertise.

We should ask VR to take 5% of their staff and train them on ASD. Few hours training would be a lot better than none currently.

Are we familiar w/ what VR providers in terms of training?

Essentially zero. I spoke with the director VR and she knows that they are not doing a good job placing individuals w/ ASD—80-90% of the time they fail in finding them jobs.

Can you explain a little bit more what it means for VR to be failing in finding these individuals jobs? Is it VR's job to locate a position that the client can seemly fit into? And would families say VR is failing to find me a job or are they saying that VR is worthless in preparing my child for the job?

So according to the survey-only 10% of the time did VR find them a job- from VR's perspective (I am not expert but have some reasonable knowledge about this) they are providing services and the expectation is they are going to get the client a job - so they hire agencies like SARRC or others to be VR providers just like how DDD hires agencies. They have a support coordinator that decides what services you are going to get—career explorations, ppsc eval, skill eval, etc. But ultimately the main mission is to find a job for that person. The agency is contracted for job placement and then they get a bonus if a person stays there for 1 month, 3 months, 6 months, etc. (I forget the exact timing)-basically the longer the person is there the more a bonus they get. If people are not successful at finding a job the less interested they become in working with them...the perception I have (and I talked to other families) is generally VR staff has no knowledge on ASD and working w/ individuals w/ ASD. You need to know what career you want when you go to VR- example- I want to be a policeman-VR can then help you get the training. So you have to come to them with a job or career goal in mind...they will not give you \$ for tuition unless you know your goal.

I don't mean to defend VR-I don't know that much about it-but when I see numbers like 80% of families saying that VR was not helpful to me, I start to wonder how much of that is emotionally based and how much factually based.

And provider based. What kind of resources they have to get the job?

And part of the issue is VR is saying here are all the people that are providing this general type of service. But they cannot suggest one agency vs. another...b/c of federal laws and regs..and b/c most of these agencies are for-profit companies that are seeking government contracts..

I guess I can understand on some level if they said here are all the ASD agencies and you select one of them-and they cannot recommend one agency or another...but from your point about ASD training...

Could this be an additional recommendation?

Yes this would be a great recommendation—make a list of ASD knowledgeable providers—that would be a huge benefit to families.

It would also be useful to give information to families that show how useful the agencies are in terms of placement. So that parents could have clues on which ones are more successful.

Also having a list of ASD providers would be helpful b/c it might force non-ASD listed providers to want to get ASD training to get on that list. You are on this list if you do training.

We have to do something about the rates for the providers. I see so little of this changing unless we or DDD or anyone providing services for adults - we need to put additional value on the people that we are hiring. We can come up w/ a million different ideas but if you don't have people to implement them...

Specifically how much do you want the rate to increase?

Frankly I think rates should increase for kids too. There is a big problem in reimbursement and tracking people across the board. But I almost think that you should pay a premium on the adults b/c there are lots people that want to work with kids but far fewer with adults. The demand for people that want to work with adults is much lower.

We could ask VR what the typical turnover rate is

One of the ways we are trying to do better for services for adults is that we aligned our services so that we are doing to same quality for adults. So for the first time we are seeing staff that worked with kids become interested in working with adults. But we have the fund that through fundraising and we also fund that with levels through insurance contracts and a little bit of higher rates on what we do for little kids. So we are reinvesting some of those funds to help the adults. We need incentivize ASD agencies that work with little kids to start getting into the adult services. SARRC has done that b/c it's part of their mission. But it's not easy..There are lots of ASD providers but few that work with adults. I don't know what's better, do we want providers that know little about ASD to start learning more about ASD? Or do we want people that have experience with ASD but have no experiences with adults?

The high school teachers are available during the summer.

75% of special ed aides have second jobs. They work past school time. I don't think too many of them are job coaches. But I know plenty that could be.

VR is paying job coaches about \$15/hr this could be an attractive salary for special ed. aides

I think one of the complex issues around adults is the concept around group supported/shelter based employment. What are some of the recommendations you are considering about the direction people are moving in employment? And there is also this knowledge that we have high expectations but have huge individual differences.

One of things we were surprised to see is that people are in general happy with CBE employment. I think the salaries are very low - average \$3/hr. – hoping to get more work—the staff I saw at CBE facility are gentle and work well with the individuals there. But there are not the right people to go out and get jobs for the people there. Need an aggressive sales type person to go out and get work to bring into the workshop. And we don't have the funding to get that sort of person.

Overall this data shows us the drastic need to improve transition services prior to leaving the public education system. 75% of the survey responders have left the education system many years ago. But only a handful obtained a professional level position w/ most working services level jobs. In a time when our focus is on transitional services, don't seem to do it well. What this workgroup needs to do and what all the workgroups need to do is come up with recommendations that correlate universally—and one of those is the need to improve transitional services. We need to work with individuals at the earliest possible age and cover as many spectrums as possible so they are actually prepared, they have work experience, coaching on how to find a job, etc.

Recommendation-Some high schools have work-bridge programs where you spend a couple of days each week during the last two years rotating in different job positions off campus. Some high schools have this-but many don't. Also tends to be more for higher functioning kids.

If people can read through the recommendations and send us emails on anything that needs to be changed so that we can iterate on it the next time-the other thing I would like to suggest is to take this survey and draft recommendations to the head of DDD and VR and ask for their input before we give it to the governor.

We need to tell Monica Courey and Sara Salek we want to do this.

Couple of suggestions-include % on the bar charts and explanations that were included on the survey about the different programs in the survey report.

Sharon will send out topic areas discussed at previous meetings re conversations with adults with ASD to get their input

We need to create a resource website to allow parents and providers to search for resources and find answers to questions. I think it would be a great outcome for the full workgroup/committee

Where do you think this website should be housed?

I think a non-profit. I talked w/ AHCCCS about it but I don't want this website to be just an AHCCCS site. I think it could be more robust than that. It could be a parent support group, an adult support group, etc.

It sounds like we can do something broader- we don't have simple handouts by DDD on housing options—maybe we can have a housing resource guide. I thinking having short guides on multiple topics can be the direction we take.

It would seem like that would be a great way to put all of these expertise together.

Also a guide for colleges/community colleges

We need to get the word out more.

I think it will be a big project b/c you have to keep it up-to-date. One way to make things available, what agencies to go to.

When agencies give you list of home provides-it's so long-it's overwhelming—you can tell which providers are better than the other.

Alani can you lead me to website that has housing information on it?

Yes I can get that information for you.

Where do we put all of these reports?

This might be possible to seek a grant to fund the website.

I think it would be better if we can get a few key agencies that are working on it together in same manner as we disseminated the survey.

We should include links to guardianship information

Coordinated integrated physical and behavioral health-what is the thought of this workgroup on recommendations around that?

In general, trying to implement a medical home model makes sense - generally group home will work with the doctors

How do people transition from pediatricians to physicians who treat adults - we don't have developmental family providers- physicians needs resources and help

Do family practice doctors get trainings on these topics?

There is such a high interest –I think there is a need- these are places that are open and knowledgeable- this would require population health management- provide a place we could coordinate those services.

If you take a developmental physician and allow them train family practice doctors and let them be listed as such

Self restricted diets- feeding therapy- this would be very appropriate service for AHCCCS to provide

The concept of integrated wellness services- we are trying to develop it for diabetes

We saw that massage therapy - anxiety is the biggest mental health issue

Is cognitive behavioral therapy covered by AHCCCS?

We contract through DHS - the RBHA is the contractor for BH treatment.

Can you see if they provide cognitive behavioral therapy?

Lifestyle health/lifestyle services- only if they have a team that could support them-the social interaction- quality of life issues- we are soon going to have plenty of adults

Is there research re social support and higher satisfaction and better health outcomes?

- There are a lot research that life style intervention shows improvement in health outcomes
- CBT studies would show reduction in medication use
- Good data on program called Peers-CBT-SARRC is doing a pilot
- Project Search-shows a high success with regards to high job placement-and has been adopted for NY-this will probably lower some cost
- People go to hospital b/c they need meals

Marsha Mallick has some of the best longitudinal data- I will provide this report

My recommendation- we need someone to look for jobs for them

Eliminate the gap between DDD and VR

Need for work experience

Need accommodation for ASD symptoms

Finding and keeping a job- categorized into- job coaching and training- support for job- teaching interviewing and application filling skills- need understanding

Job shadowing

Any other themes-

Other needs- when parents pass away who will look after these children-especially when you don't have a family member who can look after them-maybe looking at fiduciary non-profit-

The general topic about future planning

What do you want to share with the full committee with the November 18th meeting?

We need to make the biggest recommendation that have the largest impact on our population.

We think about resources and how to best use it-the high turnover rate for group homes

Housing; social group therapy will need more support than that- raising the rates for quality intervention

How do we get strategic about the recommendations?

- PCP receive and experience barriers
- The tidal wave- we don't have the infrastructure to support these individuals who are transitioning to adulthood –start incentivizing providers to move and build infrastructure needed to support these adults
- We have
 - o Social issues
 - o Housing issues
 - o Medical issues

Do we want to communicate via email? – Yes

Do you think a recommendation is building a resource database-with links?

Would It be helpful look at the topics you have – which ones are the most doable and which ones have the biggest impact?