

**Comments made during Kansas Community Forums/Focus Groups,
Stakeholder Meetings, and Interviews
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Introduction

The basis for this information is: Multiple community focus groups held over a four month period March, April, May, and June, 2015 in the vicinity of Salina, Wichita, Kansas City, Lawrence, and Topeka, three Stakeholder group meetings with Providers of Services, State Officials, Self-Advocates, Formal Advocacy Groups, Parents, Guardians, and Family Members, and dozens of interviews with interested persons living in Kansas. ***Over eighty people with developmental disabilities made up a part of these comments*** and their comments are spread throughout every category. In every instance privacy, including the location of the commenters, was attempted to ensure candor. Safely, these comments come from more than 350 persons and accurately reflect the concerns of nearly all Kansans interested in the Employment of citizens with disabilities.

The following list of comments was transcribed from the words spoken at the time the comments were made. There is a potential for errors in transcription that is not recorded, again, what was sought was the highest degree of honesty and candor, uninhibited by the limits of being recorded. Each comment was listed but one time, even if it was mentioned multiple times, verbatim. We purposely didn't want anyone to be careful about what they were saying and made every attempt to elicit how people really felt at that time about employment and potential barriers to employment for citizens with significant disabilities in Kansas. In most instances, the comments were made publicly.

Limitations:

- 1) Some of what is said is not and may not be true, but the perspectives expressed were genuine and it is felt that every participant was speaking the truth as they perceived it to be.
- 2) No one was asked what they thought was going really well and should not be changed because this question will likely be addressed subsequently.
- 3) Everyone wasn't interviewed, almost all of the information was derived from persons having an interest in the employment of persons with developmental disabilities, a few concerning the employment of citizens with behavioral health needs, and just one who spoke about similar issues for persons with physical disabilities. Although the specific details of the needs of Veterans, persons with brain injuries, and children of working age with mental health needs were not sought, it is believed the experiences and thoughts expressed by persons easily represented similar experiences of all Kansans with disabilities. In fact, due to HCBS waiver and the Supported Employment initiatives that began more than 30 years ago with persons with developmental disabilities, it is widely believed that persons and families of persons with significant disabilities other than developmental disabilities experience more barriers to employment in Kansas than those expressed in the community focus groups and stakeholder meetings.
- 4) The purpose of this project by design is narrowly focused to ensure sustainable systems change, change that becomes the customary and ordinary way to go about this work of ensuring citizens with significant disabilities are employed in their communities. Persons with disabilities, their families, and the business community will benefit from permanent, routine, and sustained daily actions by state officials and providers of services—the smart use of all of the taxpayer's dollars.

5) This work is focused on what happens with the more than half of a billion dollars spent by Kansas taxpayers every year on behalf of citizens with disabilities and it is specifically not about, neither criticizing or supporting initiatives, pilots, or assuredly noble-intentioned projects current and past to get people with disabilities jobs. As with many states, there is always something going on in Kansas that promises to lead citizens with disabilities to a better quality life via employment. There are far fewer efforts, like this one, that focuses on ***how we customarily and ordinarily spend the overwhelming bulk of taxpayer dollars everyday in the Developmental Disability, Behavioral Health, and other disability service systems, almost exclusively Vocational Rehabilitation and Medicaid***, to ensure citizens with disabilities do not live in poverty because he or she works, pays taxes, and makes a living wage.

The comments were de-identified and sorted into the following categories in no particular order of importance. Because a comment is under a particular category, like for example “School/Education Comments,” this does not mean the comments came from teachers or other school personnel. It is just a comment about that area, schools/education, or students. Some of the comments are profound, thought-provoking, inflammatory, hopeful, courageous and extremely insightful, some all at the same time:

1. Waiver/Medicaid Comments
2. Vocational Rehabilitation Comments
3. Parents/Families Comments
4. Employment Specialists Comments
5. Systems Comments
6. Employers Comments
7. School/Education Comments
8. Providers Comments
9. Friends Comments

Those comments that just didn't seem to fit anywhere were usually put in the Systems Comments category. On occasion a comment will appear twice, in different categories by accident or design. Nearly every comment offered was done so with an extraordinary degree of passion, compassion, emotional intelligence, and, that indescribable unless you've been there, infectious Kansas humor. It is the opinion of many researchers that the following information, known as "raw data" from interested citizens living in a democracy is as close as possible we can get to discover the truth known as "The Wisdom of Crowds."

Waiver/Medicaid Comments

People encouraged to select from I/DD waiver options, not work.

New funding mechanisms, getting rid of the milestones and the tiers, can fix a lot but they must be accompanied by policy enforcement.

\$12.24 doesn't incentivize follow along to help people keep their job. Providers want to be paid for a full day service, so the provider can decide who does follow along and how much they'll get paid, and the provider still gets paid for the full day no matter how many hours the person is working or failing.

Self-directed services in Kansas does not allow negotiated rates.

HCBS day service providers can refuse services to people with autism or people who use wheelchairs.

BASIS determines what tiers you get put in. It has nothing to do with your support needs.

Tiered funding, differing rates, and a lot of different levels is too complex inside the tier, only allowing and limiting just a certain number of hours.

Waivers, currently say the money should be pooled at the provider level, not individualized.

Certification programs are needed to make Employment Specialist and Job Coaches a profession with better pay.

DD funding Tiers determine everything, the services, how big the check to the provider is, the individual's needs are not considered, the provider's costs are not considered.

Tiered rates are not working, they limit the number of support hours a person can have without knowing the persons exact needs.

The HCBS waiver is effectively frozen regarding employment by VR in Kansas, all of their delays is the equivalent of denial, so the person just goes to the sheltered workshop or center.

HCBS waiver funding structure must be completely changed.

In the last half of the 1990s the priorities changed to offering families choice, and they chose day centers and sheltered workshops to keep their adult children and the SSI check safe.

Once they took away funding flexibility, got rid of state only funds, and everything became the Medicaid waiver with limited services, there has been no change, no rate increases in 7 years either.

A major change happened in State Medicaid that stopped believing people could work.

VR and Medicaid rates are so low that people don't have access to employment services anymore, providers are dropping employment services and just doing facility services because they are losing too much money.

Medicaid HCBS waiver is seen as a way to reduce services rather than a way to employ and develop people. Either you work or if employment ends you go on HCBS services, in facilities. HCBS services are seen as facilities in the day and group homes at night.

The state got Pushback from CMS on wanting to set a work criteria.

System is perfectly designed to support what you get—in KS, system is designed to get sheltered work.

SE isn't happening in I/DD waiver; use has gone down recently; more congregated sheltered stuff.

Medicaid Buy-in has plateaued—not just I/DD—across Medicaid; very generous terms for individuals; no work requirement—in terms of hours—right now.

Focus has been on fitting people into jobs, instead of Customizing. If systems could be redesigned to allow this—more effective services.

Unintended consequence of waiver—how providers set up programs; expectations of families

Data may not reflect individuals in SE—SE may be funded under day services.

Used to have more flexible funding, not with match...Less flexibility with Medicaid.

18,000 transition age IEPs in Kansas public schools, but only 8000 receiving services through all time in the DD waiver

56.5%: State/Federal match, means we are one of the more well to do states.

Tiered funding structure (DD) gives more influential agencies level 3 and less influential level 4 funding for same people.

No flexibility since they took away all the state funding. It's now all Medicaid with just a few services. What people really need isn't offered.

DD funding Tiers determine everything, the services, how big the check to the provider is, the individual's needs are not considered, the provider's costs are not considered

Pay up-front financing needed to encourage provider economic stability and hiring more employment specialists.

May require re-design of KanCare to provide services above 1115 Waiver and C waiver (already doing some)

Targeted case management through CDDO's, not MCO's with I/DD Waiver

160 people in Tier 1

44 people in Tier 5

“Shared Living” (Like Foster Care) Under Residential Programs

No Communication or Knowledge of what each agency does

KS is at a low point in cooperation/interaction--need a venue for this—talking to each other; come together

Historically I/DD waiver went in direction of sheltered workshops

Segregated settings—hard to move away from; Financial incentives for it

Within KanCare—ability to provide above or non-waiver services—How do we expand this?

Dollars are capped, so use money in ways that meet unique needs. Maybe beyond traditional menu of waiver services

Only self-direction around attendant services, should be expanded to all services

Because of waitlist, people develop bad routines, families need support & take what's available (Workshops?)

Day program funding is supporting Employment—more flexible for providers—providers get paid the same even if the person loses almost all of their hours, providers claim they're still working!

Supported Employment is a service designed for Employment-only providers, group home providers have a conflict of interest.

Sheltered Workshops subsidize Supported Employment

Lack of follow-along supports for including people in community life, not just job supports.

In the 1980s, thirty years ago, there were 2 pots of money: Disability services and Community Living/Community Employment. Then it got combined into 1 and employment isn't a priority.

Persons with Autism and Behavioral Challenges can't find a service provider that will take them.

Everyone is really a #3 tier, or they become a #4 tier when they cut services

Out in the community four at a time, 4:1 ratio at day rate, pays better than SE

Kansas relies on group employment settings, enclaves

Employment Specialists, and the whole system, needs skills training on what individuals with disabilities, their parents, the community, and businesses value

Funding requires face-to-face contact in order to bill at \$12.24 per hour for support and follow along, so you know providers aren't doing that much or they'd be broke.

Higher paying jobs, not just a job.

Increase funding going toward employment.

People with disabilities who use wheelchairs could use more bathroom assistance.

Getting access to services is easier if you choose a group setting.

Community services may not offer 1:1 support like you can get in a sheltered workshop.

Tier funding limits the amount of support and follow along funding, won't allow enough funding to cover the follow along support costs.

Self-directed services in Kansas does not allow negotiated rates.

BASIS determines what tiers you get put in. It has nothing to do with your support needs.

Need to enhance relationships with Business to Business Development Councils.

Not paid for generic job development, not paid for targeted person specific job development, not paid for person specific time at all, must be face to face.

Funding requires face-to-face contact in order to bill at \$12.21 per hour for support and follow along, so you know providers aren't doing that much or they'd be broke.

New funding mechanisms, getting rid of the milestones and the tiers, can fix a lot but they must be accompanied by policy enforcement.

\$12.24, they don't pay \$12.24 an hour, my rate sheet says \$9.00

More than just a job, but other community supports to be a member of community
Keeping connections is important.

Transportation money should follow the person not the facility

People are put in silos for them are you SE or Placement or Day?

One waiver for Group homes, most have 4 + residents

Funding streams all have different rules and agencies dictates to follow

56.5%: State/Federal match, means we are one of the more well to do states.

May require re-design of KanCare to provide services above 1115 Waiver and C waiver (already doing some)

Targeted case management through CDDO's, not MCO's with I/DD Waiver

"Shared Living" (Like Foster Care) Under Residential Programs

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\$ are capped, so use money in ways that meet unique needs. Maybe beyond traditional menu of waiver services

Only self-direction around attendant services.

SE isn't happening in I/DD waiver; use has gone down recently; more congregated sheltered stuff

Belief of providers that \$ is theirs, not individual's with a disability—workshop business model—why refer out if \$ may go elsewhere; harms the business model

Group homes—"most" 4 + residents

Systems flaws with money incentives—Can't make \$ on employment

We need to change how we spend \$

Making the community accessible—Increase social capital and connection

CMS—how to do this in a way participants are ok with it

People with disabilities who use wheelchairs could use more bathroom assistance.

Getting access to services is easier if you choose a group setting.

Need creativity for people to compete fairly—need support from state.

Training and education needed in state—currently send staff out of state for training and education

Low funding

Nebraska's funding results in longer staff tenure

Vocational Rehabilitation Comments

65 Rehab Counselors—75 total current capacity, not allowed to hire anymore or pay them anymore.

Only option to get on waiver is to go through VR & work

People with disabilities have had humiliating experiences with VR, labeling them as unemployable, having to go out on their own to get the jobs they have today to prove them wrong.

VR Supervisors and Counselors come and go.

Counselors don't get back to person needing services and won't contact provider who referred them, saying it's a conflict of interest. Meanwhile, counselor and supervisor turnover, person doesn't get services.

The purpose of Vocational Rehabilitation is to get people out of poverty.

If you'd see a VR Counselor's desk, stacks, stacks, and stacks, you'd see what's wrong.

I don't know anyone spending money on supported employment these days.

Under the guise of giving people more choices, they refer people to providers with no experience doing the work and they just leave people hanging.

It was working in the 80s and 90s, we were doing it well, then they switched us to performance based payments and then our performance went out the window because it wasn't enough to pay for the cost of somebody good to do the job.

Not paid for generic job development, not paid for targeted person specific job development, not paid for person specific time at all, must be face to face.

New funding mechanisms, getting rid of the milestones and the tiers, can fix a lot but they must be accompanied by policy enforcement.

VR and DD should consider presumptive eligibility and stop spending a fortune in taxpayer money to determine whether someone who went to Special Ed and who's been disabled all his life is really disabled, get rid of the mandatory 30 day assessment.

The guy in charge in our region is despised by the counselors so nothing gets done and they're all leaving.

There are fewer people going to VR services than ever before, maybe not enough counselors is the reason.

People have lost all confidence if they go to VR that anything is going to happen.

VR is sometimes asked for more hours of job coaching to help the person learn the job, the answer is usually no, when it is yes then 30-35 hours are authorized, never more than \$1000 worth of additional job coaching. Providers do it for free until they can't afford to do it anymore.

It would all work better without VR, just use day funding to get and keep the job.

Milestones, pay for performance is not working. Providers cannot afford to get people jobs because the pay is too low.

VR expected the providers would do most of the onsite job coaching with the milestone payment money and was surprised to find how few hours of job coaching the provider is doing and can afford to do.

VR could offer benefits counseling, but won't.

VR policy says 18 months before graduation, but only shows up 6 months before.

VR paperwork takes a long time to get back.

VR and the DD system treat Aging out Foster children differently than they do other children. The adult services process doesn't begin until age 18. Foster Care is privatized, when they age out they leave the Foster Care system, not transferred to the adult system.

The \$4500 in milestone payments are meant to pay for the provider to find and get the person a job, it doesn't pay for job coaching, job coaching is paid at an hourly rate of \$34.

Providers do about an hour a month of job development on each person.

VR keeps coming up with new initiatives to spend money, or sometimes trying to spend money, on things that don't work. So they send the money they don't spend back to the state and don't bring in the federal money, to look like the good guys helping with the state's deficit.

VR will not pay for any services if the person is still a student in school

VR services are not available in some areas of western Kansas.

Endeppence is their latest idea. It's supposed to get a couple thousand people jobs over five years for \$25,000,000. How is that suppose to happen with no current provider capacity, the people who knew how to do this left the providers years ago, and VR still thinks their milestone payments and job coaching rates are fine. This money will just roll back to the state most of it unspent as usual.

The VR process takes so long that the job is lost before funding happens, it takes months and years sometimes to get through the process.

Vocational Rehabilitation view is that people can and should work in a real job in the community vs. sheltered workshop view is they can't, not enough jobs to go around out there.

Vocational Rehabilitation used to be right of worker after work injury, but this was taken out of law so it is up to the employer and/or the worker's insurance carrier whether they want to pay for Vocational Rehabilitation. If they refuse, the injured worker may ask the state rehabilitation administrator to refer the injured worker to a provider of such services, to be paid for at the injured worker's expense, not at the expense of the company where the injury occurred or the injured employees insurance provider.

Bidder's preferences, KEPI, and other initiatives do not pay providers enough to use them.

Vocational Rehabilitation will only pay if the person's employment success is guaranteed independently, if it can't be then they are crossed off the list as unemployable.

For every dollar the state puts up, the federal government will send Kansas four dollars, but Kansas hasn't matched the federal amount in years in VR. The conservatives in Kansas must like giving their tax dollars to New York and California, I'm sure they match.

Vocational Rehabilitation Services are limited to only 90 days.

Vocational Rehabilitation Services are limited to about 90 days after the person reaches Status 22 before they're closed in Status 26, stability.

There is no limit on the number of days VR authorizes.

VR implementation across the state is inconsistent, turnover and no counselors in some areas.

Regional Director of VR they used to have in Wichita worked with providers.

Getting people with disabilities jobs takes time to invest.

Parents with disabilities are told you don't need supported employment you just need to get a job.

Providers are routinely stopped from acting on opportunities by VR, and the job is lost

Only option to get on waiver is to go through VR and work.

Endeppendence is a new Kansas Project (VR + Matching funds, state partners provide \$; 5 cabinet level agencies coming together (commerce, corrections, KS Dept of Health & Environment, KDADS, Voc Rehab)

WIOA—Looking at how VR can participate in IEPs, may look different because of WIOA, VR may need more staff.

Work program has some flexibility on how much they pay.

Stronger collaboration between VR & schools earlier

Students need Paid Jobs

VR should be there prior to last 6 months of school

VR has 18 month written policy, counselors say 6 months but can't tell people they can't provide services sooner than 6 months, because caseloads, 145 are too big, wish the state would implement order of selection.

Good VRCs are dropping like flies.

VRCs have a caseload between 120-160, up to 200

Number of VRCs is very inadequate.

VRCs are told they can't have a second job.

VR is telling parents/students that they can't fund any services at anytime while student is in school

Need more VR counselors—revolving doors—transition counselors—high caseloads no CRC

VR counselors are dropping like flies—structural/management problems

- salaries
- 32K-38K/year
- can't hold 2nd job

One VR vendor is owed \$40K.

Year and a half to get a new counselor when counselor leaves---120-160 to 200 per caseload

Transition needs to be looked at differently—not preparing for adulthood. Need to do it earlier; younger.

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Better opportunities for collaboration after VR closes cases.

VR does Job tryouts—80 hours subsidized ages; 20 hours job coaching.

Competency: VR should be required to give a list of placement rates for providers so individuals/families can choose competent providers.

VR has said that job coaches need master's degrees and we will pay them less.

VR audit: how was \$ spent? Didn't talk to a single client

VR needs to ask those on the ground how to make things work—need to be listened too...

Use Discovery to get to know the person.

No rehab association, use to be one in Kansas. Lots of collaboration use to occur there. VR no longer can participate. VRCs want to; upper management problem

Dept. of Commerce is wonderful—put VR under WorkForce

VR requires CRCs within 7 years, but position tenure averages 3 years.

Providers Comments

Belief of providers that the \$ are theirs, not the individual's with a disability, they run a workshop business model, why refer out if \$ may go elsewhere and harm their workshop business model.

The only thing providers are really offering is a group home.

Providers are losing staff with 60% turnover, wages can't support them

Financial disincentive when individuals become more self-supporting, provider agency loses money.

Providers holding on to segregated employment model for folks with significant disabilities.

Providers are financially better off with group models; Hard to beat financially lucrative group ratios

Providers can bill every minute when individuals are in Workshop, but can't bill at all when they have natural on-the job supports.

People are put in silos for providers, are you SE, Placement, or Day?

Bigotry of low expectations: Providers need to have higher expectations and changed attitudes.

Providers are routinely stopped from acting on a job opportunity by VR and the job is lost so VR doesn't have to pay anything.

Providers have had lots of training, and lots of staff turnover, after people get trained they leave.

Representative payee's role complicates things, sometimes this is the residential provider agency that may shy away from the benefits complexity and adjustments necessary with employment. The person may have to sign over all the money he or she makes if they live in a group home anyway.

Employers are inundated with unplanned saturation by job applicants whenever a job is open. There are no memorandums of understanding or agreements among providers or providers with the state.

State blames providers and the providers blame the state.

Employers may see people as dirty because some of the provider staff sees them that way.

Recycling jobs, sorting trash, is the only jobs people with disabilities can get.

Providers are not funded to make people more independent, just to be paid to take care of them so they don't have to be in an institution.

Pay is \$9.25 to \$10.00 per hour, can't get people to work for these wages, tried to recruit people from overseas but they wouldn't work for these wages either.

Provider agencies and State agencies are no longer hiring people with disabilities, hiring persons with disabilities is considered by them to be a burden.

Provider agencies and the State puts people in stereotypical "for the disabled" jobs, taking out garbage and trash, sweeping and mopping.

No training for "soft skills," skills other than direct on the employer site training.

Project Search is in 4 sites and should be expanded.

People with disabilities want jobs and more money, are paid nothing or hardly anything now.

Online application process is seen as a barrier, people still going through interviews rather than Supported Employment or Customized Discovery employment methods.

Fast food don't pay, start at 30 hours, now down to 1 hour a week.

People need to speak up and tell them their stories.

Coworkers make fun of us while we're working on the job.

Provider jealousy and competition, if another provider gets one of "their people" a job

Lack of support among providers, case managers, and VR counselors for employment, they all require readiness proof.

Job development is just sending out applications to employers everywhere.

Providers are giving them once a month paychecks, discouraging.

People with disabilities have a hard time getting a job, need support getting a job.

People with disabilities need to tell people what work they want to do instead of just being thrown into an open spot.

Providers, families, VR, and everyone really discourages people from thinking about real jobs, says we are just dreaming.

Getting people with disabilities jobs takes time to invest, the state funders don't understand what the providers know.

People with disabilities don't get jobs because they don't do well in an interview.

People with disabilities are put in groups for convenience.

Agencies make a lot of money off of people working in workshops.

People with disabilities should be able to work 40 hours per week too.

Budget cuts means job coaches must use their own vehicles to transport people back and forth to work.

People with disabilities need different types of jobs than cleaning and fast food, their dream is not to be somebody else's garbage man.

The only friends people with disabilities and their families have are provider agencies and paid advocates. Employers, Church leaders, Business leaders, and Political leaders are missing.

People come off waiting list into a group home and get whatever services are available with that provider.

Need an analysis of the staff turnover costs related to employment. How low pay and people leaving stop the process, drags it out, have to do the same work and ask the same questions over again.

Some providers just want the state to give them the money so they can pay whatever salary they want and do whatever they want with whatever is left over.

Providers need to know how to speak skillfully about integrated community employment.

Standards and quality checks are needed, to ensure fidelity of our employment practices.

Employers are inundated with unplanned saturation by job applicants whenever a job is open. There are no memorandums of understanding or agreements among providers or providers with the state.

State funding sources don't understand this work, don't know all that it takes to get someone a job, about the importance of relationships with employers and businesses.

Persons with Autism and Behavioral Challenges can't find a service provider that will take them.

Need to enhance relationships with Business to Business Development Councils.

We do place and pray today, and poison the [employer and businesses] well, by paying the staff \$8.75 an hour.

Providers try to work with the easiest people that don't need much support because with the milestone payments they can't afford to be out there very much.

Providers try to pay job coaches and the follow along people the least they can because they can't afford to pay a lot and go over what the milestone pays.

Providers try to get people in the easiest minimum wage jobs that don't pay very much and aren't very many hours because with the milestone payments the costs of paying the person has to come under what they get paid from VR.

Providers need to change how we do job development to educate businesses and city leaders.

Sheltered workshops subsidize supported employment.

Financial disincentive to providers when individuals become more self-supporting, providers lose money if someone moves into a tier of services with less support.

The only thing a provider offers is a group home.

Providers are losing staff with a 60% turnover rate, the wages they pay don't support them.

Some providers are using state funds to keep people employed.

Providers get the employees they pay for.

Supported Employment is a service designed for employment-only providers, group home providers have a conflict of interest.

Providers pay follow along support workers \$7.25 an hour minimum wage.

Tension between Providers and their staff. Providers have their own business need to consider, can't afford good staff who'll want more pay. No provider increases in 8 years.

Heart Strings in Overland Park, have employment programs under a bigger umbrella

The MCO's staff are people that moved from agencies because they couldn't do some of the work at the provider agencies they worked at before, at the agencies their hands were tied.

Providers are conflicted, complicated, those who pushed Employment First are also for an "array" of services, meaning day centers and sheltered workshops, because the individuals and families want them.

Be aware of pushing too much, allies may have a hard time supporting too much change because of their current investment in facility based services.

Keep in mind, change is threatening to providers, they are invested in buildings and concrete services, they're resistant

Out of state providers, like ResCare and Mosaic are out of state organizations that run CDDOs too.

Providers and funders have low trust levels with each other. Providers are worried about change, they're reactive to proposed changes, wary of any change proposal

There's a problem with coordination between providers and employers.

VR pays \$34. Providers pay employees between \$8-\$17 an hour based on level off education and tenure.

The way we are trying to get jobs isn't working, companies never respond after reading the resumes we send them.

Providers are interested in how to transition from sheltered work to community employment.

Low rates for providers are an issue.

We need competent providers, need to rework policies to ensure they are competent.

Provider agency staff looks at my employment department fearfully, afraid I might move folks.

The real fear providers have is not serving individuals and families the way they originally promised.

Within an agency, inter-departments look at employment fearfully because if people work then they may want to live independently in the community and need less supports.

Providers want to know if the work takes place off of regular programming hours, like evenings and weekends, will the regular programming day hours still be filled.

While online training is good, what providers need is on-site support (face to face).

Providers are afraid if they collaborate then their funding will be jeopardized.

MCO's control KanCare, they can change the rules on providers.

Parents/Families Comments

Philosophical framework of low expectations has been learned by parents. Without holding parents to the same high expectations, without it, hard to build new policy.

Vision and expectations of parents need to be changed, parents need to know the truth of what happens when their child is an adult in a segregated group home they never imagined.

Parents need an educating seat on city councils, parents need to be taught to advocate early on and sustain their advocacy lifelong.

Parents fear putting their child through failure, their child wants to be with his or her friends that have disabilities, both the parents and the adult participant want to be around others they already know.

Education Services end, there is a loss of security, their adult child is now alone.

Parents want them to just be with their friends, like when they were children.

Parents fear that the person assigned to work with his or her son or daughter in employment hasn't had enough training.

Parent fear their son or daughter will be alone out there in public with someone who isn't as educated as the people who were around him or her in school.

Parents fear because they know their son or daughter hasn't been prepared to work.

Parents fear because their son or daughter has no real work experiences, hasn't had even a real paid part-time job before.

Parents know and fear their son or daughter and they themselves will not have or get the supports necessary for successful employment, so why do it.

Parents and guardians need training and education on benefits, now they see employment as something that causes a loss of benefits.

Parents are afraid of letting go, just want day centers and sheltered workshops.

Need more ways of doing this, more opportunities in rural areas and smaller towns.

Families need a network of other families who children are integrated in the community and working, sharing success stories.

Low expectations of employers, families, schools, and persons with disabilities themselves: can't work and make enough to make it worth enough to try, just go to a disability facility and a disability group home for the rest of your life and let people who don't have disabilities work.

People need to speak up and tell their stories.

Education needed for whole family, siblings, grandparents, etc.

Education Services end, there is a loss of security, their adult child is now alone.

Parents want them to just be with their friends, like when they were children.

Families need a network of other families who children are integrated in the community and working, sharing success stories.

Adults with disabilities are treated like lifelong children, when an adult with a disability is seen in the community without a staff attendant or paraprofessional, authorities are called. In public school para professionals are constantly beside the person

There has been a shift in rights and responsibilities with parents and others forgetting the responsibilities. I just want him to be happy, work might be hard.

Every one wants guaranteed and protected income and are afraid of losing benefits.

Parents and Providers Concerns: Safety, security, stable income (SSI)

Only option to get on waiver is to go through VR & work

Help parents see the bigger picture, their child will be healthier and live a longer active life if working.

Help parents understand all the pieces required for community employment.

The only thing offered to the family is a group home.

Parents have had seen their children have bad experiences individuals in supported employment and they want other options.

Create a vision for parents—help parents see possibilities.

All experiences are unique to the individual—alters expectation.

Golden egg: get off waiting list—this is the end, not what those services can do, or what they are meant for.

Everyone still wants people with disabilities to be kids, people with disabilities want to show people what they can do as adults.

Parents feel there is more support in a facility setting.

Some parents don't want kids to work because of fear of benefit losses.

Parents want day filled, 9am-5pm; Residential wants day filled.

Do families even know there are opportunities other than a group home?

Our kids need to know they can contribute; are valued, that others value them.

Parents are actually ok with movement to community settings, this change is ok, parents want a plan.

Group home = safe/controlled environment.

We should value families and the independence of the individuals.

Value families as collaborators, people who know the person best, use families well and appropriately for the individual.

Need to stop being complacent.

Families of adults raised kids in a different time, different service options.

Parents don't know of alternative/education/training/work.

Day program/workshop fills the day.

Once in, then routine—hard to remove.

Parents don't know most effective tools—current best practices.

Parents come from a history where there were not alternatives—no public schools; families may have debt for example, and happy to not have to worry about their kids.

School/Education Comments

Leaving education system without working is a great harm—those are the years when we gain the foundation of work.

Schools are having special educations students doing work experiences in businesses, helping employers as job shadows, working without getting paid, setting a precedent that people with disabilities can be free labor, why pay for it?

Schools often use a teacher with no training as a paraprofessional just to watch people at the employer's business.

People with disabilities are segregated "for their safety," families and paraprofessionals "do for" so no one knows what he or she is capable of.

When education services end, there is a loss of security, their adult child is now alone.

Schools provide student labor to businesses for free and always have a paraprofessional beside him both in and out of school. No wonder employers look at you funny when you ask them if they want to hire people with disabilities.

Education services for 18-21 year olds depends on the school system, onsite, offsite, employment or not, volunteering, almost always grouped, not individual services, services only during school hours, only work or volunteer during school hours never on evenings and weekends, commonly work in businesses without being paid.

Teachers don't ask at IEP meetings what community job students want after graduation, they ask do you want to work in a community job or not?

Teachers ask at IEP transition meetings, do you have services set up? What services do you need? They don't ask what kind of work do you want to do after graduation.

Parents use to school transportation, school provided breakfast, school lunch, after school snack, after school day care and fear loss of these 10 hours of support when their child grows up, they want a similar adult day facility to take care of them.

School has paraprofessionals that provide 1:1 support, doing a lot of the work in non-paid cleaning jobs for businesses, businesses believe this free labor will continue. If it's not free then they don't need the hassle.

Teachers don't know but need to know their students can be working adults.

Education funding has been cut right where the process should begin.

Adults with disabilities and their families are all alone, not together as one like they were in schools.

Schools shifted from what type of work would you like to do, to, do you want to work? We need to shift the question back.

No state law requiring transition support, not required to invite VR into transition meetings, it's a VR capacity issue.

High School High Tech, Georgia's partnership with private businesses, we need paid apprenticeships for work.

Schools need a stronger collaboration between VR & the schools earlier, prior to the last 6 months of school.

Students need to be in Paid Jobs

Project search doing well but schools don't have resources for job development
Some students in some districts get limited unpaid work experience

District money getting cut. Looking for research on the number of work experiences needed

Olathe has work experience program for 18-21 year olds, but they are not getting jobs

Need families educated on impact of work on benefits

Olathe in 1978—kids left with work knowledge, partnered with summer youth programs.

Transition from school to work should start earlier, connection with summer youth employment programs.

Schools offer 18-21 pre-selected volunteering.

In 1978 students considered "Trainable," 18 of 25 high school age graduated with jobs.

Transition needs to be looked at differently—it's not preparing for adulthood

Transition needs to happen earlier; younger.

Challenging at home, so don't do laundry at school for example.

7th/8th grade, start thinking about career.

Summer employment at 14, like in Missouri.

System Comments

State Systems haven't adapted to federal changes yet: WIOA, CMS Final Rule, USDOJ Olmstead and ADA interpretations, to discourage "services that have an isolating effect"

There is an attitudinal barrier that really doesn't believe people with disabilities can make a living wage through employment, you can throw money at it but nothing will change unless this belief is addressed.

We need consumer buy-in, financial power to purchase their own services, to buy the new ways to deliver services.

Funding streams all have different rules, dictates to follow, uncoordinated and confusing to providers, discourages employment services.

MFPI will be consolidating data, grouping different people together under the same data so you can't tell whose who or what's what, treating everybody like they're the same.

Kansas is at a low point in cooperation and interaction, we need a more permanent venue for this, talking to each other, coming together.

Recommend that the Employment First Oversight Commission re-envision funding of employment services.

Some individuals are using state funds to stay employed.

Transportation is needed especially in rural areas.

We are getting what we are paying for. Paying nothing, getting nothing.

Our only friends are the DD Council, SACK, ARC, Leadership Center, Families, Together, Interhab, DRC (disability rights). The State agencies are not friends of people with disabilities.

We need a vision.

No state law requiring transition support, inviting VR to education conferences

Employment First Legislation not being honored or implemented: 4 years ago words don't match actions, actually going backwards.

Within KanCare it has the ability to provide other services, even non-waiver services, when can we expect this going to happen, when can we expand this?

Because of waitlist people develop bad routines, families need support and take whatever is available, whatever is available, and what's available is a workshop placement.

Transportation is a major barrier.

State officials lost focus on the investment of taxpayer dollars and its impact on supported employment to help create taxpayers.

Thinking all experiences are unique to the individual alters expectations.

Systems lower expectations for families to keep their accountability bar as low as possible.

This system's golden egg is to get off the waiting list. This is the end, not what services can do, not what services were meant for.

Affordable accessible housing just barely exists.

Services should be more than just a job, but other supports to be a member of the community, supports and services shouldn't be working against each other.

In some places people can have whatever they want, group home, day services, just not employment.

20 plus years ago SE was happening, but once person centered planning started employment wasn't emphasized, making friends, having fun, doing things you were interested in was, so we have lost staff with employment expertise going back 20 years.

Tech-Ed, students with disabilities are not included, need a Quota

The purpose of employment is to not be in poverty.

Everyone wants guaranteed and protected income and are afraid of losing benefits. People with disabilities want to not be in poverty. Group Homes need them to stay in poverty to draw down Medicaid.

RCEP/TACE centers went away so people stopped getting training, nobody get the training they need anymore.

Exorbitant cost sharing, requiring people to give up everything they make if they have a job and the live in a group home is a misinterpretation of the law.

Ask the Kansas Department of Transportation what they are doing to provide accessible affordable transportation for persons with disabilities.

Employment is victim to the self-esteem, not skills, movement, feel good about yourself.

Standards and quality checks are needed to ensure fidelity of our employment practices.

BASIS assessment just documents weaknesses and is really for people in nursing homes. It doesn't assess the person's strengths, interests, or current support capacity.

The State, VR, DD, and Medicaid doesn't want to acknowledge the skill it takes to do employment. They want to pay Employment professionals, job coaches, and follow along support professionals the same as day center staff are paid, like they are paraprofessionals.

State funding sources don't understand this work, don't know all that it takes to get someone a job, about the importance of relationships with employers and businesses.

People with disabilities are told you don't need supported employment you just need to get a job.

Choice destroyed employment, the parents chose day services.

Adults with disabilities are treated like lifelong children, when an adult with a disability is seen in the community without a staff attendant or paraprofessional, authorities are called. In public school para professionals are constantly beside the person.

System must be changed to stop our slide backwards, to create flexibility

No flexibility since they took away all the state funding. It's now all Medicaid with just a few services. What people really need isn't offered.

DD Reform Act created 27 CDDOs and the same time that VR went top Performance-based Milestone payments, emphasis went off employment and on to group home expansion.

People come off waiting list into a group home and get whatever services are available with that provider.

Nursing Care Facility Institutions (RCFs) are already the norm for mental health treatment in Kansas.

People in government in Kansas, meaning Developmental Disabilities, Mental Health, Medicaid, and Vocational Rehabilitation stopped believing in the last half of the 1990s that people with disabilities should and could work.

System believes people will need this kind of 1:1 support forever, working people becoming independent is a dream world.

People live in gated communities and everyone is fearful due to media constant reporting of violence instead of good on television. Parents see group homes and day centers as safe havens.

State government needs to support Discovery in customized employment.

Families Together, KS APSE, Beach Center, are our friends.

No one is against employment, just not a priority.

VR may not be supportive of Supported Employment, likes initiatives that nobody uses better. Makes it look like they're trying even if they really are not.

People with disabilities need coworkers, not just other people who don't have jobs either.

People who use wheelchairs can work in real jobs in the community too.

People with disabilities need to respect themselves.

System Discrimination.

Community Education.

We're different but still human.

Everyone still wants people with disabilities to be kids, people with disabilities want to show people what they can do as adults.

I don't think anyone is accessing employment services anymore, they just try to get their child in a group home.

VR and DD system treat Aging out Foster Children differently, the adult services process doesn't begin until age 18. Foster Care is privatized, when the age out, when they can't get money for them anymore, they leave the Foster Care system.

They are not transferred to the adult employment system. You can find some of these children that nobody wanted in the prison system or already dead.

Nursing Care Facilities, institutions called RCFs are already the norm for mental health treatment in Kansas.

DD Reform Act created 27 CDDOs and at the same time VR went to performance based milestone payments, emphasis went off employment and on to group home expansion.

Kansas is missing its social contract that commits, expects, and accepts social inclusion primarily through employment.

Different rates should be considered for persons with autism or persons with behavioral challenges.

A panel of people with disabilities, a speaker's bureau, is needed to inform everyone about integrated employment in the community.

Nobody wants to change anything right now. Everyone's afraid if money is shifted then it won't go to where it's suppose to go, it will just be gone to pay for the state's tax collections shortfall.

The plan of letting the businesses off from paying taxes.

Now we have to pay higher sales taxes on everything we buy.

System must be changed to stop our slide backwards, every year since Employment First our employment outcomes have gotten worse instead of better.

The will to get people with disabilities jobs is there, but we can't find our way.

Representative payee's role complicates things, sometimes this is the residential provider agency that may shy away from benefits complexity and adjustments necessary with employment. The person may have to sign over all the money he or she makes if they live in a group home anyway.

Employment is victim to the self-esteem, it's your choice led by case managers, movement, feel good about yourself.

Families have 90 days to say yes to a group home slot and the day services that go with it or lose that slot.

Words don't match actions. They say this new initiative or this new \$500,000 or several million dollars will make things better, but why don't they just do the everyday work right and stop coming up with some new scheme that doesn't work.

We need to educate legislatures new and old alike on what's going on.

Kansas has lost its creativity and spark. We need to start with the expectation of integrated community employment.

We need to have all stakeholders to be on board to redo incentives. VR doesn't think they're getting their money's worth out of the milestone payments now. Group homes would rather be left alone. Everybody's doing fine, except the people with disabilities themselves who don't have a job, or any money, just stay in poverty. Medicaid thinks it costs more to offer more services.

Hard to have a vision when you see limited options.

Do away with subminimum wage.

We need a safety net: 3 out of 10 don't succeed in their first job if we do a good job, the good news is 7 out of 10 do. 6 out of 10 fail if you don't do a good job, but 85% succeed on the second try.

Advocacy is too quick to guardianship, self-determination means choices, failure and experience learning.

Just refocus the money on the things that work and stop creating some feel good sounds good thing that is just about blaming the providers for not participating and giving the money back to the state to balance the budget.

The rates are too low.

State legislature is uninformed about individuals with I/DD, 5 of 40 are very young.

State staff have been put in positions without expertise or knowledge.

Community thinks Medicaid users are using unneeded services.

MCOs have control over KanCare for the next three years.

Kansas is dealing with paranoia of administration
Administration is using groups against each other

Braiding & Blending money is unheard of, no one cooperates

State agencies afraid if collaborate then funding will be jeopardized, if you act like you want to work together and share it it means you don't really need it.

MCOs control over KanCare—3 year contracts.

Kansas Medicaid saying it can't get expanded Medicaid because needing money to get individuals off of Wait-List.

Scarcity mentality—Zero Sum Game: Example schools and VR won't work together.

Collaboration incentives don't exist, low trust culture for good reason.

Collaboration will be helped by informing families about resources/tools available to request.

No educating families who can't read efforts or who can't speak.

The team vs. "Our Team" mentality.

MCO's who control KanCare can change the rules on providers, everyone keeps their head down, low profile until this storm blows over.

Even Johnson county has a provider capacity issue—not tons of employment providers.

Fear and Safety concerns are well-known.

Success stories, Jobs, own homes, etc. aren't talked about.

Employment Specialists Comments (job developers, employment training specialists, and job coaches)

Going rate of good Supported employment pay is \$10-\$12 per hour with \$8-\$10 more like the average hourly wage for employment specialists.

Follow along support workers make \$7.25 minimum wage.

Skills needed: systematic instruction, assistive technology, marketing, employment law, customer service, Sales, Accommodations, but the people they got doing this only have a high school education.

We need to change how we do job development to educate business and city leaders.

We need stable support staff, have 60% annual staff turnover.

Employment Specialists, job coaches, job developers must be paid at the start \$30,000 to \$32,000 per year. They should be making at least \$15-\$16 per hour.

Wages are even being raised at Wal-Mart above what we pay, how will we compete?

Today we have double paperwork and half the pay.

Need an analysis of staff turnover costs related to employment. How low pay and people leaving stops the process, drags it out months and months, have to do the same work and ask the same questions over and over again.

If they'd wake up and pay Employment Specialists \$25 per hour then suddenly wha-la, we would have all of these skilled people who know what they are doing getting jobs for all of these people.

Employment Specialists should at least make more than a bus driver at \$13.00 per hour.

Employment Specialists wages too low for skill requirements and expectations, should be between \$30,000-\$50,000.

Staff turnover is 60% annually, almost everyone who worked to help support someone is gone in a little over a year.

There's not enough people who want to do this work, let alone at a starting salary of \$10.00 per hour.

Low pay, devalued work, vulnerable people, equals poor outcomes, potentially dangerous for people with disabilities and their families.

Tried to recruit overseas workers to come to Kansas the way other businesses do to get their work done at a price we can afford to pay, but none wanted to do this kind of work.

Job developers need trainers and don't have them, after we help them fill out the applications.

Job coaches need people to get them the job so we can train them.

Better educated and qualified job coaches.

Need reasonable accommodation for online applications.

Job developers are focusing on and talking about the person disabilities to employers not capabilities.

Case managers need a much better understanding of employment, they don't have any, just say it's up to you, your choice, you need services all during the day.

Connections, relationships, use of discovery, should be used to get jobs not answering help wanted signs.

People with disabilities are discouraged from thinking about their dream job, rather than encouraged.

The way we are trying to get jobs isn't working, companies never respond after reading our resumes.

Certification programs are needed to make Employment Specialists and Job Coaches a profession with better pay.

We've had a lot of training and a lot of staff turnover, after people get trained they leave.

Employment Specialists should make \$20 per hour plus benefits.

Employment Specialist are leaving to go to work in other states.

Doing good work, getting good outcomes costs more than current payment structures.

The problem is low pay in Kansas.

There is a lack of cooperation and collaboration in how to use our low funding.

Employment Specialist should be professional enough to educate and market to businesses, to make it easy for businesses to hire people with disabilities, to offer supports to businesses and the individual on an ongoing basis.

Friends Comments

DD Council
DRC
SACK
GHA
APSE
Interhab
SILK
Dept of Commerce
BLNs
Down Syndrome Guild
Mission Project
Johnson County
OMNI
Lives matter
COF
TARC
TILRIC
P&A
Work program
Work is Healthy
United Healthcare
Amerigroup
Sunflower
MaryEllen
The Cabinet Secretary
Craig, Steve, Elizabeth
Presearch foundation Wichita
Disabled Vets Association
Families Together
SBDC
DDC
Disability Rights
APSE
MissionProject

OMNI
LOF
WorkForce Centers
SILC
ILs
Down Syndrome Guild
TARC
Kansas Focus
Minds Matter
Employment 1st Oversight Commission
SBDC
Johnson County Community College
TICRC
Work Program
United Health Care
Sunflower
AmeriGroup
Cerebral Palsy Research Foundation
UCP

Employers/Businesses Comments

Huge problem with keeping relationships with employers because funding doesn't allow support follow along services, even though folks will need the support sometimes.

Need to enhance relationships with Business to Business Development Councils

Employers are inundated with unplanned saturation by job applicants whenever a job is open. There are no memorandums of understanding or agreements among providers or providers with the state.

Employers need to be able to access a type of funding so they benefit directly from the time, attention, and training they are providing the new employee who has a disability.

Employers were taking on the responsibility for free, and now they won't.

Different rates should be considered for person with autism or persons with behavioral challenges.

A Panel of people with disabilities, a speaker's bureau, is needed to inform everyone about integrated employment in the community.

Employers don't give people with disabilities raises as they do other people.

Finding employers that are willing to hire people is hard, everyone's been out there asking them already.

Employers won't hire if they can get students and their para pros to come out and do it for free.

Employers need training to improve their perspectives.

Employers fear liability.

When people with disabilities get sick employer says I don't need you anymore.

Employers think people with disabilities should be paid the same as anyone else doing the job.

Employers help people with disabilities when they use to work for them, they are good references, they are people who will support people.

People with disabilities need more than just a job, they need a career, to be good at a job, not just have a job.

Businesses should be offered incentives to provide apprenticeship training.

Businesses/Employers need incentives for them to hire, everybody in human services gets paid to help people, yet we expect businesses to help them for nothing.

Employers need to be able to access a type of funding so they benefit directly from the time, attention, and training they are providing to the new employee who has a disability.

Employers were taking on the responsibility for free, now they won't.

Businesses anymore don't believe they can trust staff from the disability providers, the training and consistency is less and less.

Employers are confused by the role of the job developer, the employment specialist, the job coach, and the ongoing follow along person. Seems like a bait and switch.

Employers need information on how they will benefit. Why should we do this?

Employers should be integrated in the process, not in job fairs, from the beginning to the end.

Employment Development Councils not Business Advisory Councils

Employers must be incentivized, be paid something, or this is not going to work.

Employers need to be brought in to contradict preconceived ideas people in human services have about them.

Employment Specialist's task analysis could help businesses with all of their work and employees.

Businesses have the perception that they are doing us a favor, work us a few hours like almost like we're still in school working for free.

Businesses and many other community leaders needed to be involved.