

Report on the Working Age Adult Policy Focus Groups

Prepared for the King County
Developmental Disabilities Division

Submitted by:

O'Neill and Associates
98 Union #706
Seattle, Washington

Candace O'Neill
Teri Johnson
Joyce Black
David Black

March 2006

Introduction

This is a report to the King County Developmental Disabilities Division on information gathered from 29 participants at three family focus group sessions. The purpose of the focus groups was to gather information on questions and concerns related to the Working Age Adult Policy.

The focus group sessions were led by a facilitator and a scribe to record participant responses to six questions.

- 1. The Working Age Adult Policy raises the following questions and concerns for me...*
- 2. I need more information or clarification on the following...*
- 3. What I like about the policy is...*
- 4. I have heard that the policy will...*
- 5. I would be less concerned and more comfortable if the policy...*
- 6. Other things I would like the county to know about the policy...*

The participants generated information on what families are concerned about related to the policy; information or clarification they need on elements of the policy; what they like about the policy; what would make them less concerned and more comfortable with the policy and other things they would like the county to know regarding the policy.

Summary

The family focus group participants generally supported the Working Age Adult Policy for individuals that are capable of employment. They are concerned that the policy does not take into consideration the individuals for whom employment is not a realistic goal at this time. They also question whether there will be sufficient resources available to support the job development, job coaching, personal care needs, and follow along services that will be necessary for individuals to be successful. Families are also concerned that services for individuals with severe disabilities that are not employment related will be of lesser quality and not a valued service and that individual choice is not being honored.

General Themes

There are several themes that were shared by most of the participants.

Nearly all of the families are concerned that the policy does not address the needs of individuals with severe disabilities that may not be employable. They would like to see more options, such as volunteer work and community integration, and the flexibility necessary to meet the needs of everyone.

Families are concerned that their son/daughters have tried many jobs and have not been successful. They question whether the supports will be there to make the job placements successful.

Families believe that there is insufficient funding to adequately pay for the supports individuals with severe disabilities require to be employed.

Families believe that this policy holds people with disabilities accountable for the success of others who are integral to employment such as teachers, case managers, employment agencies, and the business community.

Families would like to see sections of the policy more clearly defined. They want to know how the exception to policy will work. They want clarification about the role of the Case Resource Manager in deciding whether an exception can be approved or whether a person is succeeding with their plan. They want to know more about the Pathway to Employment plan; the definition of the term "generic community services", and the definition of "gainful employment".

Items of Interest

About one-third of the families questioned whether all people should be able to choose an option to "gainful employment".

Families in one session asked whether mileage funding could be used to pay for innovative services for people where employment is not the goal?

Families asked why the focus groups are being conducted so long after the policy was signed.

Some families questioned whether this policy is the best use of the limited funding. Some people wanted to see more information about the cost/benefit.

Some families would like to see a comparable policy that defines high quality of life services for individuals that cannot work and identifies valued activities and expectations.

Some families believe that the policy needs to result in greater collaboration between parents, schools, service providers, and the business community to prepare people for work.

Some families think that the policy needs to acknowledge the needs of people with challenging behaviors and provide the supports they need to be employable.

Some families would like to have an appeal process in place.

Several participants questioned how this policy fits with Social Security and the Division of Vocational Rehabilitation benefits and whether their participation in a plan for employment will compromise a person's federal or state benefits.

Family Focus Group Session Notes

The following are the notes from the three family focus group sessions.

Session #1

South Group/Hampton Inn
February 21, 2006

Session Description

There were six participants in this focus group, three mother and three fathers.

Participant Responses:

1. The Working Age Adult Policy raises the following questions...

Participant #3 (see prepared notes)

- The commitment to the policy may be by dedicated people, but they may be single focused and not understanding the needs of all.

Participant #2

- It is good to plan for support for those that are interested and able, but for those that do not have the health or interest, it's not fair to have the rigid policy. To be able to get the self-esteem and other benefits attributed to working, people should be able to get those needs met in non-work activities. Other considerations should enter in.

Participant #1

- It seems unfair to expect our children to work as "wards of the state" when welfare recipients are not required (people may be expected to work but are not required to work).
- It is unclear about whether someone would "have to" work. How will it be financed? (Agreement of group that funding would be an issue.)

Participant #6

- I have tried to get my son into programs a number of times and have tried various forms of technology. He needs to be tube fed and is not toilet trained. I am currently paying \$23/hour for someone to take into community. How would this work for him? What would an exception to policy involve?

Participant #4

- We have to remember the uniqueness of each individual. This policy does not allow for the individual differences of people.

Participant #5

- Policies are written by people who are not in our homes. Our daughter has been through special education, work study programs, assessments and all reports point to her not being employable. Just getting through life is work for our daughter. The CARES assessment further points to her deficits. Last year averaged about 50 visits to doctors. She is on multiple medications and it is very difficult for her to leave the house. I don't feel she would fit with this policy. People cannot know how her life is and how this wouldn't work.

Participant #3

- There is a disconnection between people writing the policy and people who understand what life is like for us. How can they understand what is best for your child. People (policy makers) don't get our stories.

Participant #3

- The policy makers should be hearing this directly. They should be in this meeting. My concern is that you end up with intermediary [the focus group team] that delivers the information. Having this focus group causes me concern that we are sharing with you and not with those who directly influence the policy.

Participant #1

- This report will dilute our comments and not convey our emotions.

Participant #4

- We have to re-qualify every year and it is overwhelming. The process can be overwhelming to individuals and their families. I am primarily referring

to the CARES assessment. This compounds things. It means more work and tasks.

Participant #5

- We have been getting Leslie “ready for work” for 30 years. It hasn’t worked so far. What I know about getting her to 42, I can’t imagine how she will change by 62.

Participant #3

- We have to consider life expectancy. What consideration is given to the differences in aging? If my child is likely to have a shorter life, should they be held to 62 as age of retirement?

Participant #5

- It seems that the policy is written for healthy, non-disabled people. Majority of people are not typically healthy.

Participant #6

- What about those people who will not reach a cognitive age of 18 years. There are child labor laws – what if they have IQ that is lower?

Participant #4

- Who is this supposed to benefit from this policy? It doesn’t sound like it makes fiscal sense.

Participant #1

- Where will they find the employers?

Participant #5

- Current issue in legislature is transition; I would suggest that the focus and funding go to that group. Do that well – and then focus on others.

Participant #3

- Overall, efficiency of dollars spent is not being monitored well.

Participant #1

- There is not enough money now. What will happen to currently funded supports?

2. I Need More Information or Clarification on the following...

Participant #6

- I need more info on what "generic" services means if people are unable to pursue or gain meaningful employment.

Participant #5

- What does gainful employment mean? It is unrealistic. My daughter would not be able to fit into generic services.

Participant #3

- I would like to see a cost benefit analysis of the Working Age Adults Policy by an outside party.

Participant #3

- Where does the authorization to withdraw services come from?

Participant #5

- Is July 1st an absolute deadline? Is it negotiable?

Participant #1

- Is the County being pressured to promote this policy?

Participant #5

- What would be the supports necessary for someone else to prepare my daughter to do things that I have not been able to do?

Participant #1

- How does this fit with choice?

Participant#5

- I need clarification on how Case Resource Management fits into policy.

Participant #6

- I need clarification of how the exception to policy would work.

Participant #2

- What does “Pathways to Employment” mean?

Participant #3

- Who were the stakeholders that the Policy refers to? How can we find out who they were [representing families]? Is there a document that could be reviewed for this information?

3. What I like about the policy is...

Participant #6

- That they are giving people the opportunity to have jobs, it just shouldn't be “one size fits all”

4. I have heard the policy will...

Participant #2

- I heard that the policy will force every person with developmental disability to be working.

Participant #2

- I heard that people will lose their benefits if they don't opt in and that services could be cut off.

Participant #6

- Individuals, by being employed, will be less dependent on services, tax dollars, etc.

5. I would be less concerned and more comfortable if the policy...

Participant #6

- I would be less concerned if the policy was written with input from people who are “living the life” and if it were individualized.

Participant #2

- I would be less concerned if the policy were written with consideration of the entire population of people with developmental disabilities and to the uniqueness of each individual.

Participant #5

- I would be less concerned if we could talk directly to “policy” makers and have answers directly; we don’t want special treatment, just to be understood.

Participant #3

- I would be less concerned if the policy includes employment as just one of the pathways to a meaningful life.

Participant #1

- Why are we just now being asked for input if it was signed in 2004?

6. Other things I would like the county to know about the policy...

Participant #1

- It stinks. I think I have said enough.

Participant #2

- DDD spent a great deal of time and money trying to figure out employment. What is the purpose of trying to revisit that 20 years later? She has deteriorated. At this point there should be other options supported. Agreed by Participant #5 and Participant #6

Participant #5

- What I would like to have happen would be for the County (support person) to take the person “by the hand” to figure out what would work. Give us the support that will be needed for the policy to be fulfilled. Participant #6 agrees. Participant #3 agrees.

Participant #3

- What about the need for fiscal responsibility? There should be a more cost effective way of offering meaningful activities. Supporting many of our children would draw significant resources.

Participant #6

- How will this effect our Guardianship reviews if we voice that we are against this policy? Could it be viewed negatively by the courts? If we don't feel it is in the best interest of our child could our Guardianship be challenged?

Participants #1

- Would there be legal implications if our daughter makes a choice since she is her own guardian?

Session #2

Highline Center in Bellevue

February 22, 2006

Session Description

There were seventeen participants in this focus group, fifteen family members, one family member with developmental disabilities and one representative from a special care agency.

Participant Responses

1. The Working Age Adult Policy raises the following questions...

Participant #3

- Will the ratio of Case Resource Managers to individuals be able to handle the number of people that are unserved?
- Of the total population of people with developmental disabilities there is a minority group that will not ever work. Will people eventually lose supports if they don't actually get a job?
- All of group agreed with above statement (14).

Participant #5

- I've been told that the supports and money are not available to support my daughter. She is not able to say whether she wants to work.

Participant #6

- Could this eventually lead to losing other services? Perhaps leading to losing waiver status?

Participant #3

- The policy language is not clear.

Participant #1

- There seems to be a philosophical perspective that everyone will work. Making all fit doesn't include everyone. The policy seems to be based on a population that doesn't exist anymore there is a much broader group of people accessing services. People with more significant disabilities are at home with their families now, not in institutions.
- As an employer, co-workers and customers must see the value/status of a person's contribution. Suggestion for my daughter is that her caregiver takes her out to the park and ride lot and pick up trash while daughter watches.
- The essence of the policy needs to be broader to accommodate the range of individuals and I don't think it should be addressed through an exception to policy. People shouldn't have that as the only avenue to an alternative program.

Participant #14

- Most of my daughter's friends have not been successful in getting employment. My daughter needs job coaching. She wants to work, but because it has been difficult to find the right job her hours of job coaching were cut. She needs personal care and physical assistance with toileting. Everyone I know has been left out in the cold.

Participant #7

- My son wants a job desperately, but they have not been able to find a job given his support needs.

Participant #10

- This policy does not match the economy. My daughter was laid off after years of work due to cut backs. The work and jobs are not there. My daughter has tried several times and every time there is a set back it takes three years to bring her out of depression.

Participant #5

- People need to think long and hard about impact of this policy on individuals and families. It is devastating for those with mental illness when they lose their job.

Participant #3

- This policy needs to address those who are least likely to be considered for employment. Paid providers need to have policies that match the expectations of the Working Age Adult Policy.

Participant #15

- There needs to be more choices and options. Close to 80% of our adult clients want to work – but they will need on the job support, those supports are not there.

Participant #1

- Another problem with the policy is that by its existence it means that employment will be the focus. There will not be development of other activities that will be meaningful and add to the quality of people's lives. The exception policy is not a very well thought out process.

Participant #6

- People who do not have gainful employment will be cut from other services. Families are trying to do a juggling act to keep things together.

Participant #7

- We went through a process where our son lost all eligibility. It was very difficult to repair.

Participant #6

- I want to have the exception valued. We currently have put together a good situation for our daughter, utilizing county services. I don't want to lose services.

Participant #5

- My daughter found her own job with the City of Seattle. She lost that job and went into a 3 year depression. She is desperate to find a job and wants it very much. How will she have the support for gainful employment? If my daughter loses her job who will be responsible?

Participant #14

- I heard that after July 2006, those people in volunteer positions will lose their support. Does the Pathway to Employment allow for volunteer positions? Many of our kids have volunteer positions. Is their support in jeopardy?

Participants #11 and #14

- The goal is gainful employment and to have people support themselves. How can that happen when non-disabled folks are not able to make a living wage working full time?
- The policy could ultimately punish the individual if the agency is unsuccessful. It is the individual who will suffer the consequences.

Participant #5

- I have concerns about how the business community will respond, there seems to be limitations or capacity issues. Is there a market being developed?

2. I need more information or clarification on the following...

Participant #13

- How about folks who pose significant danger to themselves or others, particularly those with behavior issues, how will this be addressed? What will there be for them?

Participant #11

- What criteria or measurements will be used to define gainful employment?

Participant #6

- What is meant by an employment plan – what will it look like?

Participant #14

- The policy is based on successes – what about those have not had success? We just don't fit?

Participant #11

- What is meant by generic community services?

Participant #9

- Social Security says gainful employment is \$900 per person how will this be affected?

Policy #14

- The policy needs to include everyone. It doesn't include our people.

Participant #2

- Quality of life should not be dictated or defined by someone else. Don't take structure, security and safety away.

Participant #3

- There needs to be a better explanation about how exceptions will be processed and a better definition of who will qualify and how they will be decided.

3. What I like about the policy is...

Participant #11

- The pressure that is being put on school districts is good.

Participant #1

- From the state's perspective it is putting pressure on the system to develop more and better community based services.

Participant #14

- It is good that individual choice is mentioned.

4. I have heard the policy will...

Participant #14

- If you don't follow the policy you will lose benefits.

Participant #1

- I am concerned that the policy will be a disincentive for programs and services for people that don't work.

Participant #14

- I am concerned that volunteer work won't be valued, that it won't count.

Participant #3

- Transportation needs to be considered.

Participant #5

- I am concerned that the policy will create instability.

Participant #7

- Will Case Resource Managers have the final say in what happens? Is that true?

5. I would be less concerned and more comfortable if the policy...

Participant #13

- I would be more comfortable if there were benchmarks for progress, criteria for success and a template for use in assigning resources.

Participant #1

- I would be more comfortable if there were a counterpart for those who don't fit. There needs to be something in policy for those who will not work due to their ability or choice. What will there be for them?
- I would like to see a comparable policy for those individuals that cannot work that identifies valued activities and expectations.

Participant #3

- I would be more comfortable if there were more accountability for those placing folks in jobs and following up when there are job losses.

Participant #13

- I would be more comfortable if there were more oversight of vendors and better tracking of the dollars.

Participant #5

- I would have less concern if there was money to support the policy.

6. Other things I would like to county to know about the policy...

Participant #5

- It is a great policy for those it fits, but it doesn't fit some and there is no allowance for that.

Participant #1

- Local property tax provides flexibility for the County to use their discretion in perhaps funding some alternative programs that wouldn't be affected by state policy. This should be considered. That could be the flexibility.

Participant #13

- My daughter has many challenges and she is entitled to the same dignity that other people have.

Participant #14

- For people with more significant disabilities, I don't see the vision, support and dollars. I would like to be able to see the Plan for Employment or Pathway is able to be individualized.

Participant #16

- This policy would have benefited my son coming out of school.

Participant #1 & 2

- Don't forget those that don't fit, make sure they have options for meaningful lives.

Participant #4

- Everyone should have choice; if they can't sustain employment, what will happen?

Participant #5

- I want my daughter to have choices, meaningful, funded choices. I want the county to feel appreciated for what it is doing for some people.

Participant #10

- Our daughter wants to be employed and we want her to be employed, but she will never be gainfully employed. We don't want this policy to be harmful.

Participant #12

If this can be "delivered" it will be great!

Participant #3

We appreciate the county holding the focus groups to get input from families.

Session #3

King Group/Ramada Inn Northgate
February 23, 2006

Session Description

There were six participants in this focus group, five mothers and one father.

Participant Responses:

1. The Working Age Adult Policy raises the following questions...

Participant #5

- It sounds like every family will have to participate in the child's life and that teachers will have to be accountable. That it [the policy] must be adapted to fit the needs of everyone. There must be the support to allow that creativity.

Participant #6

- This policy seems to be good, but I feel that my son will leave school without being prepared for this policy. Teachers must receive the training to be able to participate.

Participant #1

- The policy seems very idealistic but not realistic. I feel there will be some people who will never be able to get jobs, whether related to their support needs or lack of creative options.

- The cost for some people would be excessive. Why can't he be supported to make a contribution where he is now?
- We will need support staff that are trained. Participant #4 agrees. There needs to be options besides career path.

Participant #3

- Families will need to step up, as they should regardless of disability, but this seems impossible for government to dictate.
- I am concerned about the schools capacity since they don't seem to be able to do this well for many non-disabled kids.
- My biggest concern is that the general idea of this is great, but it is truly "pie in the sky". Government is promoting it but it is up to the business community to employ people.
- It is not realistic for those with greater support needs. Where will the fiscal resources come from to cover the support necessary to keep individuals safe?

Participant #4

- My concern is who will be interpreting the criteria. Who will define the minimum and maximum standard?
- I have concerns about the mental health cycle issues and job retention.

Participant #5

- It seems that those with both developmental disabilities and mental health issues have been overlooked. How will this policy accommodate mental health issues?
- How does this fit with those in post-secondary education?
- I am wondering how the county system will be able to implement the supports necessary. What will the infrastructure look like? Self-employment might be an option, but very expensive to establish and support.
- I fear that the expectation of parent's time to make the employment plan work will be overwhelming. Many parents will not be able to provide the level of support required.

- Will sheltered workshops be accepted as gainful employment? Is there a marketing plan in place to develop the opportunities that will be needed?

Participant #2

- Will businesses be able to absorb the accommodations necessary (productivity and behavior supports)?

2. I Need More Information or Clarification on the following...

Participant #4

- What constitutes gainful employment? If there are mental health issues and a gap in employment will services be jeopardized?
- Where does volunteer activity fit, will it be considered as a part of the vocational path?

Participant #3

- Is there a minimum FTE level? How will periods of unemployment be handled and would that lead to a waiting period for services? Is there a way to appeal decisions? Would benefits stop and what might the waiting period be to regain them?

Participant #2

- Who is going to fund this? Seems like there will be a need to train many support staff first, who will then need to train teachers and employers. Is it possible that savings from those who won't be included will go to those who comply? (There is a shared concern about what happens for those who get and lose jobs.)

Participant #1

- What are the choices if you are not choosing employment? Why aren't there other options? Why can't people choose community access? Will that continue to be an option?

Participant #5

- Who will be responsible for educating the business owners?

Participant #2

- How many people are in that 21 to 62 category for King County DD?

Participant #4

- With CARES assessment and those needing personal care on the job how will that be funded?

Participant #6

- What if DVR has said my child is not employable?

Participant #2

- Have other state's implemented similar policies? What has been their experience? Is the federal government pushing this?

Participant #3

- Who benefits from this?

3. What I like about the policy is...

Participant #5

- Implementing the policy will require collaboration on a level not yet reached. The policy recognizes that people can contribute and be respected.

Participant #6

- The policy sends a positive message.

Participant #1

- This is a good goal its just that it neglects other parts of peoples lives.

Participant #2

- It does encourage contributions by all and if it will encourage hiring by businesses, it is good.

Participant #3

- I don't like it. It's too vague. I can't imagine how it would be implemented financially.

Participant #4

- It forces collaboration and forces links with other entities. It encourages creativity and opens doors for others. It will provide concrete examples of success.
- It is good that there is an exception option, but there needs to be process for appeal.

4. I heard the policy will...

Participant #1

- I heard that community access will be cut and everything has to be toward employment. Everyone I know [in community access] got a reduction.

Participant #2 and Participant #3

- I am hearing about it for the first time tonight.

Participant #6

- I heard about it through the consulting teacher for my son's Individual Education Plan who said we needed to focus on his pathway for the future.

Participant #5

- I heard that everyone is going to have to work except those with significant disabilities (people at the school districts "4B level" category that is for the people with the most significant disabilities) and that an exception would be given only to these folks.

Participant #4

- I've heard that this is a strategy to cut services for some in order to fund others or to save money.

5. I would be less concerned and more comfortable if the policy...

Participant #2

- I would be more comfortable if we had some sense of how this will be funded. I can't imagine how that will happen. How can it be fully implemented by July 2006?

Participant #6

- I would be more comfortable if this policy was tied into the transition process and required school transition planning at age 14.

Participant #1

- I would be more comfortable if community access would be considered as an option. It might be in conjunction with employment.

Participant #4

- I would be more comfortable if it is spelled out more clearly how the county would be working with partners.
- I would be more comfortable if there were something in the policy that recognized the need to individualize and meet needs of all people. If there were more flexibility in meeting individual needs
- What is the case resource management ratio for folks who are working age adults? How will they have the capacity for this?

Participant #5

- Bring on more awareness about DD individuals through a media campaign that would influence businesses and community members and dispel stigma and myths. For example, it would have helped more if black history were taught as schools were integrated.

Participant #3

- Where is the training going to come from for all audiences?

6. Other things I would like the county to know about the policy.

Participant #5

- I have a problem with individuals who are on disability due to their substance abuse issues (who have "caused" their disability due to substance abuse) who are taking SSI resources away from our children.

Participant #6

- I would like the county to continue to work with families on understanding and dealing with this policy. Continue having support groups/focus groups for families.

Participant 1

- Do you have a Plan B if Plan A doesn't work? I'm not feeling very optimistic; I know many others have been looking for jobs for a long time.

Participant #2

- Our kids are an asset, not a liability. It's not and should not be about money, they are individuals. There needs to be a range of options in services. Why are just people with disabilities held to such a policy; why not other groups?

Participant #4

- It feels really punitive (agreement by the group): why penalize people if they are not ready?