



King County

Developmental Disabilities Division Plan for Developmental Disabilities Services Comments on Public Review Draft

Summary

The public comments on the draft plan reflect strong agreement that the following needs should be identified in the Plan along with King County Developmental Disabilities Division's (KCDDD) role in addressing each need. Potential roles for KCDDD and the State Division of Developmental Disabilities (DDD) that were identified by commenters are noted in parentheses after each need:

School Age

- Children and youth with developmental disabilities (DD) need opportunities to participate in social and recreational activities with typically developing peers. (KCDDD: fund supports for after-school activities.)
- Youth with DD need help to establish a personal vision for their future. (KCDDD: fund training for parents in person centered planning.)
- There needs to be more effort to educate parents about the lack of supports for young people who leave school at age 18. (DDD: case managers should participate in IEPs.)

Working Age

- There needs to be day program options for adults who are unable to be employed. (KCDDD: fund day programs; facilitate parents privately purchasing needed services jointly.)
- The new requirement for periodic reevaluation in order to be eligible for ACCESS needs to be challenged due to its adverse impact on employment and access to services for people with DD who are unable to use scheduled routes.

Families

- Access to mental health services needs to be improved.
- Families with school age children need to be able to rely on schools for accurate information about resources. (KCDDD: fund training for school districts.)
- Families need to be able to easily access up to date lists of qualified vendors for all paid services. (DDD: improve web site.)

- Some families that have critical needs may not be able to seek out information or advocate for their family member with DD. These families need assistance obtaining information and advocating for supports to meet their needs (i.e. particularly senior families, immigrant/refugee families, very low-income families, families with an ill or disabled caretaker.) Senior families need assistance with transition planning for their adult children. (KCDDD: fund outreach workers to provide information and assistance; explore possibility of workers funded through Area Agency on Aging performing this function.)
- There needs to be day program and respite options for families that don't have paid services. (KCDDD: facilitate parents privately purchasing needed services jointly.)
- Families need assistance to develop shared/group homes for their adult children and particularly with removing bureaucratic obstacles.

Detailed Comments

April 6, 2005, Board Meeting

Three individuals commented:

- 1) Plan should reflect concerns of aging parents; plan should also include improving opportunities for school age youth to participate in inclusive social and recreational activities - while transition planning for employment is important, so is social development.
- 2) A lot of young people leave school at 18; many parents are unaware that services are not available for young adults 18-21 years of age. This message needs to be communicated during transition planning.
- 3) State DDD is exploring options for young people 18-21 years of age.

April 19, 2005, meeting at the Federal Way Regional Library

There were no attendees.

April 26, 2005, meeting at the Highland Community Center, Bellevue

Ten individuals attended and commented during informal discussion. Points included:

Plan should address improving mental health services for young people; parents and teachers do not recognize symptoms of mental illness. Mental illness can be triggered by any type of change. A big obstacle to providing mental health services is that providers can only treat the client, not the entire family; In addition, mental health system does not permit reimbursement for treating autism and other behavioral disorders.

A big need that is missing from the plan, but should be included, is adult day programs for young adults who are not employable (i.e. who have chronic mental illness or other severe conditions). Respite is a critical need of families, including overnight care.

There are many adults not in day programs. When a job doesn't work out some parents are unwilling or unable to try again. The Plan needs to more clearly identify and address the needs of unserved adults.

The emphasis on Social Security work incentives for young people is a concern since any paid employment under age 18 can adversely affect eligibility for SSI later on.

Page 51-52 language regarding encouraging individuals to make contributions is really a goal, not a strategy that can be put into practice. Perhaps the strategy is to use person-centered planning.

Many adults are living with aging parents. The needs of these families should be more clearly identified and addressed.

The respite system has problems that should be more clearly identified and addressed. Some families can't get public funding; Some who have public funding can't get providers. Providers need to pay for their own gas, which makes them reluctant to travel to the Eastside. The program at Highline Community College is wonderful, but it is frustrating that it has an arbitrary age limit of 18 years of age.

The Plan indicates that the ACCESS transportation program is becoming more restrictive, but is not explicit about changes. Should be clearer about what the changes are and who they are impacting. The Plan should identify and address the need for outreach to families that are unable to seek out information and advocate for themselves (due to exhaustion, poverty, health, language, culture etc.). The programmatic response to needs should not be based exclusively on the expectation that families will attend trainings or use the internet. Families can be very needy yet unable to seek out information and advocate for themselves. We need a more proactive version of parent-to parent to do outreach to families, including in refugee and immigrant communities.

There is a big gap in services for children and youth 3-21 years of age because most schools do not play a significant role (i.e. with respect to providing information about available resources, offering inclusive social/recreational opportunities, facilitating or participating in person centered planning); yet schools are the common and trusted source of information for parents. Plan should include outreach to schools.

Community Guides was very positive and should continue.

April 30, 2005 meeting at Third Place Commons, Lake Forest Park

Fifteen individuals attended and commented during informal discussion. Points included:

The estimated number of individuals with DD in KC may be higher than the estimate (based on 1.13% prevalence) due to increase in autism in the years since 1994/95 when the data for the prevalence study was gathered. In addition, King County may have higher numbers due to families relocating here due to availability of services. Plan should also caseload forecast information.

The Plan should have a greater focus on creating inclusive community-based after-school activities (i.e. training of staff and extra staffing to facilitate participation in generic programs). Right now there are very limited "slots". Systems need to be developed to accommodate children in art, science, dance classes, girl and boy scouts, beginning with the very young. DDD can not pay for everything and there needs to be a focus in the plan on developing systems that support opportunities for inclusive activities being routinely available rather than dependent upon attitudes of individual school/recreation staff. This needs to also include particular attention to summer

activities. Summer should be a joyful time but is seen as a mine field by families who do not have the supports they need when their child with a developmental disability is not in school.

The Plan should identify the equity issue of “haves” (families that have some level of state funding) and “have nots” and define a role for the county in addressing this issue. Need to have action items that go beyond just getting more DDD funding. Greater focus on collaboration with local communities and assisting them with their obligation to make activities accessible to everyone living there, including children and adults with developmental disabilities.

Page 46 – objective #3 – social security work incentives should not be identified as a strategy for ages 3-17 but rather 14-17. Add more strategies to this age group that focus on providing information about the vision of what their child will be able to do after leaving school, how their child can be prepared to leave school with a job, what natural and paid supports they might be able to access, including what they can do to build their resources/supports beyond DDD funding, such as Social Security work incentives and other resources how to prepare for accessing them.

Add strategies related to formal collaboration/working agreements with schools. Include parent and self-advocacy organizations in the development of formal interagency agreements. Establish systems that improve the flexibility of current rigid requirements (School, DDD, DVR, etc.) so can mesh funding to support individual plans. Focus on continuing and expanding collaboration.

Promote person centered planning (both formal and informal) for adolescents including training for families. Work collaboratively with families to “create the vision” of unique employment opportunities for their children so they can expand their ideas, including owning their own businesses.

The Plan should not refer to “job placements”....should refer to job and career development, choosing careers.

Support development of a process that would provide parents with easy access to current and complete lists of qualified vendors for all paid services, including Medicaid Personal Care and Respite providers (both individual and agency providers). This information should be available on the web.

The County should help promote better collaboration between DCFS and DDD so that the same services are available for a child enrolled in DDD when they are in foster care. (i.e. DDD case managers need to know how to arrange respite care for a DCFS foster child).

The County should collaborate with families to advocate for school district funding of early intervention.

The Plan should include the County taking a strong leadership role in advocating and enabling parents to develop shared living arrangements for their children, including identifying rules/procedures that are barriers to developing creative housing and independent living supports.

Work with ACCESS transportation to look at the requirement of frequent medical reviews for people with developmental disabilities for ongoing eligibility for ACCESS services. The nature of a developmental disability is that it is a life-long condition and the reviews are a burden to the adult with a disability and their families and seem to be an unnecessary public expense.

The Plan should address the issues and needs of senior families that address the unique challenges of an aging person's ability to navigate a complicated and changing support system. Possible programs include:

- Outreach to provide information to senior families in formats that meet the unique needs of aging adults;
- "Extended case manager" to provide practical help (such as completing forms) during home visits; and
- Providing mentoring/respite opportunities for adult children with disabilities living with aging parents to ease the transition to a new living arrangement should the need arise in the future.

The basic premise of the CARE Assessment is good and there is an appreciation of having a tool that makes assessments consistent. However, the County should take a greater role in collaborating with the State DDD system to make adjustments to the CARE Assessment to improve its Content Validity for children, youth and young adults with developmental disabilities of both sexes. One example was that there is not one question about personal care needs associated with menses. Another example was that behaviors related to the disability make personal care much harder and the impact of those behaviors are not addressed.

As the Working Age Adult Policy is implemented, the plan needs to have a continued emphasis on Community Access for individuals who will never have a job, who just will not be able to work....not just for people who are retirement age. Also, need to address increased need for respite, community activities and other recreational activities for times when person is not working.

Need to be sure that effective and evidenced based practices are available in all the early intervention programs across the County rather than having select agencies being the only ones that provide certain proven practices. The County must be sure that all agencies know what the effective practices are and families should not have certain services available to them at only select agencies because it puts too much of a burden

on those programs and on the families who can't get into those programs. This should be in general but also specifically for children with autism.

In providing quality services, County should also focus on "values" training for all direct service staff that support residents of King County, including the Medicaid Personal Care, Adult Family Home, Group Home and Support Living direct care staff. The training should recognize the varied backgrounds, experiences and cultural diversity of the staff and should focus on helping them understand that their supports are not just providing for the person's basic needs (of meals, dressing and self-care). It should help them to do their job in a way that promotes our values of treating the individual with a developmental disability as a full person and helping them to attain inclusion in their community.

The County DDD Plan should include developing a publicity plan that highlights stories about people who have moved out of institutions.

The County should take a lead in building community-based capacity and expertise to provide the level of professional services that have been available through Fircrest, including increasing access of Medicaid recipients to specialized dental services.

The County should work with surrounding counties to ensure that communities that are situated on the "borders" have adequate outreach, access to and enrollment in the Part C early intervention system.

April 30, 2005, meeting at Third Place Commons, Lake Forest Park

Fifteen individuals attended and commented during informal discussion. Points included:

The estimated number of individuals with developmental disabilities in King County may be higher than the figure in the draft plan (based on 1.13% prevalence) due to increase in autism in the years since 1994/95 when the data for the prevalence study was gathered. In addition, King County may have higher numbers due to families relocating here and availability of services. Plan should also include caseload forecast information.

The Plan should include providing resources for inclusive after-school activities (i.e. extra help to facilitate participation in generic programs.) The attitudes of school/recreation staff are key to the success of inclusive activities.

The Plan should identify the equity issue of "haves" (families that have some level of state funding) and "have nots" and define a role for the County in addressing this issue.

Page 46, Objective #3 – social security work incentives should not be identified as a strategy for ages 3-17 but rather 14-17.

Add a strategy regarding collaboration with school districts for supports for ages 3 and older.

Promote person centered planning for adolescents including training for families.

Parents should have easy access to up-to-date and complete lists of qualified vendors for all paid services. This information should be available on the web.

There should be better collaboration between the Department of Children and Family Services (DCFS) and DDD (i.e. a DDD case manager did not know how to arrange respite care for a DCFS foster child).

The County should collaborate with families to advocate for school district funding of early intervention.

The Plan should include the County taking a strong leadership role in advocating and enabling parents to develop group homes for their children.

ACCESS transportation requires frequent medical reviews, which can change eligibility for services. This can undermine employment.

The Plan should address the issues and needs of senior families. Possible programs include:

- outreach to provide information to senior families;
- mentoring adult children living with aging parents to ease the transition to a new living arrangement; and
- “extended case manager” to provide practical help (such as completing forms) during home visits.

An attendee submitted the following written statement during the meeting:

We are the parents of, a 29 year-old man with a developmental disability. ___ lives in an Adult Family Home in Bellevue with four of his buddies and works 15 hours per week at a Starbucks. He is on the “Basic Plus” waiver and he is one of the very fortunate people who receives services and enjoys what most “normal” people would consider a modest, but wonderfully ordinary life. The services ___ receives fit together like a “house of cards” and the loss of any of the services he receives (job support, Adult Family Home, medical, mental health, or transportation) could easily bring down this house of cards. Or put another way, a chain is only an effective device if each link is working.

We are not here today just as advocates for our son, but for the many people with developmental disabilities and their families who are un-served, under-served, with little hope of getting off the waiting lists for services. We feel the Plan does a good job of

defining the problems and deficiencies in the service system. We think we can all agree that the primary problem is a lack of adequate funding.

It is clear that the only way many people with DD will have jobs, housing, recreational and other normal life opportunities with the current funding levels are through creative solutions or what we call "pulling rabbits out of hats." KCDDD should be commended in its effort to help some people not receiving DVR or DDD funding for employment services with its "Transition Project."

What frustrates us as advocates is when we see unnecessary roadblocks in the way of people or organizations who are trying to find creative solutions to the problems outlined in this plan. Some courageous families have decided to try to create their own community residences for their adult children with DD and their friends. What they find is a process so convoluted and fraught with regulation that only the most tenacious can navigate it. An opportunity exists here for KCDD to take a leadership role in assisting these grassroots efforts at housing solutions. The process should be streamlined and a template made so other families or organizations might feel confident in creating housing for DD people.

Another area of concern for us is the frequent re-evaluations of DD people using ACCESS services. Many people are having their services cut back or are losing the ability to use ACCESS altogether. For people trying to find creative solutions to employment, housing, and recreational service shortfalls, a lack of safe transportation is a huge roadblock. The ACCESS re-evaluation process seems to be an overly expensive process. By the time most people with DD need to avail themselves of ACCESS services, their abilities within their disabilities have for the most part been established and are unlikely to change. A person with Down Syndrome, for example, will always have Down Syndrome. In addition, as these people age their cognitive abilities decline. We have seen some decline in general health and cognitive ability already in our 29 year-old, yet he was recently moved from being eligible to only being conditionally eligible for ACCESS services. Other DD people we know have been removed entirely from ACCESS eligibility even though their cognitive skills have not improved.

The "third rail" in the DD community is the issue of the disproportionate amount of DD dollars that go to people being served at the state institutions, Residential Housing Centers (RHC.) Sadly, with the power of the unions, which seem to be the main driving force in preventing further downsizing at our institutions, it seems unlikely that much money will be freed up to help DD people living out in the community.

The plight of the "senior families" is particularly heartbreaking. Our greatest concern is for parents whose sons and daughters are over the age of 35, and are still living at home, and cannot receive residential services for them. There are many reasons for this, but from an instinctive point of view, we believe many parents have simply given up and have stopped fighting. With the increasing complexity of navigating the support system, and campaigning for needed services, many older parents have become

overwhelmed by the system's complexity and have lost the capability of reaching for a life preserver, even as they themselves are losing the ability to swim for their own lives.

It is somewhat ironic, but from an administrative point of view, the elderly caregiver needs to maintain an intellect, which is inversely proportional to that of the person being cared for. The issues of documentation, finances, appointments, regulations, etc., represent an unseen burden above and beyond caring for the person. Such things are so enormously complex that even Einstein would recoil at such tasks. Then consider parents in their 70's attempting this, or even consider younger parents with limited education. These people need to be reached and to be given guidance and the funding to make things happen for them.

Candidly, we were lucky to be able to construct a plan of necessary services and supports in order to allow him to live as a reasonably independent individual. In part, these services became available by our being watchful for opportunities and to aggressively advocate and network on behalf of our son. So in essence, we succeeded through connections we made along the way. Although we don't apologize for that, sometimes it is the maxim that it's not what you know, but who you know that counts. That's not entirely fair, but is true nonetheless.

Web Site Comment Forms

Eight comments were received on the KCDDD web site comment forms. The full text of the comments follows:

Comment 1:

I live in King County and was looking through the proposed DD services for the next few years. I did not see any mention under the proposal section about Parent-to-Parent. I know that the data shows that families want and need to be connected to one another at all times during their child's life. KCDDD has generously funded the Parent-to-Parent program and I would hope they would continue. Other parents are where we get our best support, information, and education.

Also on the front page of the website it lists the Parent Coalition and Parent Training, but not Parent-to-Parent. Would it be possible to list it also on the front page with a description so families would be able to access the King County Parent-to-Parent program?

Comment 2:

I feel this already excellent plan could be enhanced by showing KCDDD's involvement and intentions around The King County Ten-Year Plan to End Homelessness.

This could be accomplished in several ways:

- Include a description of the work done in the Survival Services Homeless Project (called "Financial Assistance for Protection and Advocacy" in contract) at The Arc of

King County, that you currently support, as well as any other programs that prevent or help solve homelessness among people with developmental disabilities.

- Include statistics in Table 13 on Page 35 about the number of people with developmental disabilities who are homeless. This number may be hidden in the other listed categories as "other" and "unknown" as well as in the number listed for Residential Services because there are people who are homeless while receiving residential support services.

-Include a statement about how all the support provided by County programs and initiatives is part of what keeps many families and individuals from facing homelessness in the first place. All the programs are an essential part of the network of core human services that stabilize our community.

Thank you for considering my suggestions and thank you for all the hard work that has gone into this plan.

Comment 3:

My family is a beneficiary of the great work by many dedicated people at KCDDD and State DDD over the past 35 years. Our elder daughter has Downs Syndrome and was enrolled in Merrywood School at the tender age of 2-1/2 shortly after our arrival from California in 1969. She thrived on the outstanding special education system in Bellevue Schools, graduating from Northwest High at Interlake in 1988. She has since held several jobs with the assistance of Eastside Employment Services, the WISE program and, currently, Puget Sound Personnel Service. Beth has worked nearly 10 years for Pitney Bowes as a mail courier at Virginia Mason Hospital in Seattle, commuting to work on Metro. She lives at an Adult Family Home operated by Community Homes (founded and superbly led by John and Ann Therrien). Beth has a very active social life revolving around Highland Center activities and SKIFORALL. She loves to ski and is very proud of her association with the SkiHawks Racing Team. We often marvel at our good fortune in being relocated here amongst very progressive thinking people who are dedicated to providing a rich life for everyone.

As I read through the Draft Plan, two issues struck me as over-arching:

- More individuals with developmental disabilities need supports than can be provided with available State and County funding; and
- The developmental disabilities support system is complex and continuously changing.

These issues are intertwined in that the lack of sufficient and stable funding for DDD services contributes to the continuous changing in the available supports and, in turn, the complexity of the system. And, without the funding stability required to closely monitor support requirements, funding, planning, and justification is hampered.

It seems to me that these two issues need to be brought into clearer focus, perhaps with time lines attached to each. Establish deadlines for the identification of all needs in each population segment being served. Follow that with implementation time lines for each identified need. Funding requirements will be more easily identified and justified by this process.

As an example, let's consider those DD citizens who live at home with a single elderly parent. Referring to Tables 14 and 15, one presumes that the 105 people shown in Table 14 as "Total Number on Waiver" are included in the 2,510 people shown in Table 15 as "Total Region 4 Total." But that leaves 315 people on Table 14 as not being served, some portion of which fall into the category of "live at home with a single elderly parent." Added to that is another group of 51 people age 62 and older who are "on the waiver but not in day programs" (Table 16.) Again, some portion of that group lives at home with a single elderly parent. So, the potentially very vulnerable population of DD citizens living at home with a single elderly parent and receiving no DDD services is not clearly identified in the plan document.

I point this out as an illustration of the level of detail likely required to achieve the goal of "Meet identified support needs of individuals with developmental disabilities." Full and complete needs identification is required before all needs can be met.

Comment 4:

Chapters 2 and 3 give detailed and clear descriptions of the DD overview and supports available, thank you. I think the document would be strengthened if you would also take some time to discuss the internal structure of KCDDD/how it works (i.e. departments, job descriptions, how some strategies that say "collaboration" will work.)

- I applaud the distribution of the budget, especially less than 7% for administrative costs and a little over 50% for employment-related services. And I applaud the emphasis of goals and strategies in the areas of housing and employment.

- Personally I am the parent of a young adult with DD and mental health issues, the founding president of LifeSPAN and a member of the King County Parent Coalition (KCPC.) My greatest concerns are not in order of priority:

1. High school to work transition support
2. No state funds for persons not on a waiver
3. The number of people living with their parents (64%) and especially with aging parents.

- I know that schools struggle with inadequate funding, but it is my opinion that in general greater effort from the county in any area should be focused on the early intervention and adult populations and their families.

Comment 5:

Page 6 - The prevalence rate multiplier for Autism (from footnote 5 on page 6 Larson, S.) appears to be low by a factor of 10. In January 2005, the GAO published report number GAO-05-220 (Special Education)*, which includes an updated prevalence rate of between 2 and 6 for Autism in children. On page 9 of the report is the following statement, "Estimates of the prevalence of ASD range from 2 to 6 per 1,000 children." See pages 13 to 17 of the report for additional discussion of the prevalence of autism and other disabling conditions in children. *<http://www.gao.gov/new.items/d05220.pdf>.

The prevalence rate data appears to come from information that is more than 10 years old and certainly does not reflect current information about the prevalence of Autism.

Top of Page 10 and footnote 22: Count of residents could be closer to 28,000:

The Arc of Washington State uses a multiplier of 1.58% ** as compared to the 1.13% used in draft report. If the Arc's multiplier figure is used the estimated number of King County residents who have a disability grows from 20,062 to as many as 28,000.

**Source <http://www.arcwa.org/Who%20are%20People%20with%20DD.pdf>

Children and Adults with Developmental Disabilities in Washington State

How Many People have a Developmental Disability? Approximately 1.58% of the general population is estimated to have a developmental disability. In Washington State, this means that 97,000 children and adults may have this diagnosis.

Page 46, Objective #2 – Identify Service Gaps:

Strategies for ages 3-17. Case Managers should be encouraged to attend IEP meetings. Needs and service gaps are often discussed at these meetings and the parents feel TREMENDOUS support when they are joined by a collaborative team member who can offer to assist with needs that a school district cannot or will not address.

Strategies for ages less than 20. Work with individuals to keep them "in school" until they reach age 21. Individuals who drop out of school or who graduate prior to reaching age 21 are left with gigantic gaps in service. They are too young to receive employment assistance and have "moved out" of the school district responsibility. Case Managers or employment services vendors should be encouraged (paid) to participate in IEP planning, especially vocational planning.

Objective #3, Strategies to Fund Supports for the 3-17 Age Group:

Social Security Administration funding does not seem like a likely source of funding for most of this group.

Schools provide most services at this time in the life of a person with at disability. After school programs and parent education are mandated by the IDEA, but are infrequently provided. Mental Health funds, shared parenting arrangements, foster care, and Parks and Recreation Departments seem like more likely sources of support.

Page 47, Strategies to Fund Supports for Individuals Who Are Over The Age of 18:

Personal service providers assist elderly people with paying bills, filling out paperwork, tax returns and such. Aging parents who have a child with a disability living at home could use such service to keep track of DDD paperwork and to plan for care of their child after they die (wills and disability trusts, housing arrangements, and care plans are among the issues that get harder to deal with as we age.) Can DDD or "Aging" funding be used for these types of caregiver support services?

Page 51, Complex System Changes Continuously.

Over the 18 age group.

Aging primary caregivers – parents with child with disability living at home: Personal service providers assist elderly people with paying bills, filling out paperwork, tax returns and such. Aging parents who have a child with a disability living at home could use such service to keep track of DDD paperwork and to plan for care of their child after they die (wills & disability trusts, housing arrangements, and care plans are among the issues that get harder to deal with as we age.)

Comment 6:

On Page 6, the KCDDD paper says, "The estimated prevalence for autism is .4 per 1,000 people." This prevalence is grossly understated. The CDC, well-known for its very conservative counting, states the following on their website (www.cdc.gov/ncbddd/dd/aic/about/default.htm):

"Prevalence rate (per 1,000 children) for autism spectrum disorders among children 3-10 years of age, Metropolitan Atlanta Developmental Disabilities Surveillance Program, 1996: Autism spectrum disorders - 3.4."

And, "...it can be summarized that between 1 in 500 (2/1,000) to 1 in 166 children (6/1,000) have an ASD."

While the Center of Disease Control (CDC) includes all autism spectrum disorders, including Asperger's and Pervasive Developmental Disorders (PDD), it must be further considered that the CDC's study was from 1996 and that the epidemic of autism has exploded in the past 9 years.

Given these numbers, the KCDDD plan through 2009 underestimates the individuals with autism that it will attempt to serve by a factor of up to 15 times!

Comment 7:

Page 2 , 11 and 12: A more defined need for assistance in areas of cognition, behavior modification, judgment, and expansion of their ability to perform self help skills in the areas of dress, self care, cooperation, simple meal preparation, self direction in public places, etc. This could fall under "intermittent." This is important because once these are applied over time they become a permanent capability. These objectives should be a part of an ISP

Page 47: Create a matching funds program (much as the Dan Thompson Trust) for services with costs shared by families who are willing to do so This could free up more funds and serve more people.

Comment 8:

Thank you for this user friendly response site. I have reviewed the plan and the Report from the focus groups. Most of my concerns have been reported in the focus groups. I would like to reiterate a few points. I worked for 6 years in collaboration with the County and our school district to help create a transition program that would actually look at outcomes. We have made progress in this area and the new project with Children's Hospital is encouraging. While pleased that my daughter is in the project, I am deeply saddened as to the lack of progressive transition programs statewide and the gross disparity from school district to school district. I think a specific meeting with Terry Bergeson and the state special education staff to discuss this information would be helpful. This is the "Education Reform" piece for students with disabilities in secondary and we should be coordinating these services. Thank you for the great opportunity with Children's Hospital and real jobs.

Another area of concern that isn't addressed in the plan much is the need for transitioning youth with disabilities from pediatric medicine to appropriate adult services, including practitioners that will serve patients with Medicaid. There is a promising project at Children's Hospital looking at this.

Another hurdle for parents of transition age adults and their families is the coordination of all of the appropriate services we may be able to receive, or are signed up for. For example, my daughter has one more year in school, is part of the grant with our school district, the County and Children's. She is receiving a paycheck, she receives SSI, and now DVR wants to create a plan right now and has asked to take her "Ticket to Work" ticket for these services. She is also on the basic waiver. I'm a pretty savvy parent, but it is still very confusing. I am afraid to jump on DVR's bandwagon given the rumors. I love the idea of a more coordinated approach for the transition services into the various agencies and their services. This will encourage more fiscal responsibility and planning, support over a period of time, blending of services and better understanding for clients and families. Great idea. Another area of great concern to me is for the families that are not on a waiver but have extreme needs. As a health care professional, I have attempted to get services for two families of children with complex health needs and

DD. It was an exercise in futility. The end result was a single mother not able to keep her job that would have given the rest of the family benefits etc. This system of haves and have nots has worsened. As a provider I understand the care assessment tool very well and can document clearly why it is inadequate for children AND people with disabilities. Geriatric patients are served better but the rest just don't fit in the boxes. It has to be modified for the rest of the population. Also, how folks were moved onto them was willy nilly and inequitable.

In closing, I thank KCDDD for thinking outside the box on some of these innovative projects. This is what will lead to better outcomes. Thanks for all the hard work. Overall I think it looks like a viable plan. Thank you!

E-Mail

Two individuals e-mailed comments:

Comment 9:

Overall, I found your plan does an excellent job in providing an overview of developmental disabilities and some of the issues facing our community in the coming years. I also commend your leadership in more recent years funding housing coordination and work incentive assistance. In Region 4, I have found the case managers to be very hard working and deeply concerned about the future of older caregivers. Their comments in the focus groups were relevant and parallel my concerns about the direction the DDD system is going and the impact on our total community.

The following are questions, comments, and suggestions.

1) My first comment applies to the state definition of developmental disabilities. I am not sure that the information is accurate as of July 1, 2005, when the Washington Administrative Code (WAC) change. Given the changes in eligibility, individuals within the system and those applying for the first time (this may apply to older families), may find new challenges maintaining or obtaining eligibility. More information on the revisions should be included in the plan. If there is a space limitation, it may be best to remove some of the general definitions of autism, cerebral palsy, etc.

I recommend the King County Parent Training program offer a family training series for families and individuals of all ages. The King County Parent Coalition did sponsor such an excellent training at its April meeting. Now we need to go to families that are reached via other means than the coalition announcement.

2) I need clarification on what is meant by effective and "evidenced based," which is briefly defined on Page 2 and referenced several times in the plan (pp. 41, 49-50.) Do you have articles on research that have identified the "intended outcomes?" Do they show consumer and family satisfaction? Are all types of day programs, not just employment, reviewed? Do they include data on job loss and failure to find employment

and the costs incurred? I think the concept is excellent, but would like something in the Appendix to show what you are using to evaluate the programs. I also recommend the King County Parent Training program offer a series of trainings on these concepts.

3) Senior family references are placed within the category of residential programs Chapter 4 on Issues. It does show whether they are on the waiver, but there is no further discussion on issues they face. Nor is there follow-up response in Chapter 5, which addresses the strategies. Also, there is no mention of the role of the next generation of care-givers. Based on my intensive work with these family caregivers, both parents and siblings, this issue needs to stand alone, such as has been done very effectively in the plan for “cultural competence.”

4) The power of the Home and Community Based Waivers to create entitlements within each waiver is not given sufficient weight in the comments. It is mentioned in Issue One of Chapter 4, but without follow-up in Chapter 5. Having worked with families whose members are within the different waivers and those whose loved ones have no waiver and, in some cases, no Medical Coupon – CNP as well, the inequity is glaring. It has created arbitrarily separate classes of people (who are no different from one another in need,) a true nightmare of the haves (some with more and some with less, depending on the waiver,) and have-nots. Of course, I am most concerned with those have-nots that do not even have the Medical Coupon. Given the halt to the expansion of the waiver without legislative approval, the list of have-nots will grow. The baby boomers (parents and their children) will feel soon experience the effects.

I believe senior family care-givers whose loved ones have no Medical Coupon-CNP should be first on the list for waivers, prioritized over high school graduates that may benefit from the waiver to pay for employment but otherwise have a Medical Coupon-CNP to cover medical and in home care. I recommend this be proposed in the plan.

I also would like the plan to add more data on older parental caregivers and other relative care givers whose family members are not on the waiver, how many have no Medicaid-CNP and what services they do get (family support, employment, MPC, etc). I suggest you include similar information for those on a waiver, how many are on the different waivers, and what they receive within each section of the waiver. This data would guide allocation of funding and prioritization of waivers and services.

Another group, which may be younger but also feel the lack of the waiver, includes those who have a work history that gives them enough quarters to lose their Supplemental Security Income (SSI) and go on Social Security Disability Insurance (SSDI). If their job is lost and this occurs and the SSDI is high enough, they will lose their SSI and then their Medicaid CNP. Without the waiver, they stand to lose a lot more, including Medicaid Personal Care (MPC).

There are other related issues. I recommend that these challenges be mentioned in the plan, with strategies to address them.

Lastly, individuals and their families need to learn about the waivers. Through the King County Parent Training Program, we need to sponsor a series of trainings on the waivers. Most families I work with do not understand the importance of these programs, whether their loved one is on a waiver, and how to advocate for services within the waiver. If they are not on the waiver, or the waiver is inadequate, they also need to learn about value of advocating strongly for a "waiver slot." The training should include learning about systems advocacy as legislators need to understand the inequities of the current system.

5) Our population of individuals with developmental disabilities is aging along with their parents and siblings. Many are baby-boomers and these people start to turn 60 in 2006. In some cases they face aging related issues earlier than the general population. Yet the report says nothing about the growing health and care-giving crisis this may involve.

There is little mention of leisure programs for retirees. These programs demand increased attention. Those for whom employment has not been successful after myriad tries may also be interested in these options. They also offer a break for family caregivers.

Families need to learn about the possibilities. King County Parent Training program trainings are needed to cover the topic of aging, retirement, and leisure time options.

6) The focus groups clearly identified the discouraging aspects of the CARE Assessment Tool. The strategic plan should identify this major issue and include expanded strategies to work with the other systems for a tool that is more responsive to the support needs of people with developmental disabilities.

KCPT program sponsored county-wide trainings are needed on the CARE tool, background, assessment guidelines, how to prepare for it, and individual and systems advocacy strategies.

7) Collaborating with the aging network is critical in the coming years. There is tremendous tension between the umbrella Aging and Disabilities Services Administration (ADSA) and the developmental disabilities community. But at the County level the local AAA, ADS, is much more receptive to our issues. I have not observed nor seen in this report much effort to work more closely locally with the aging network. I suggest that this be part of the plan.

Comment 10:

THIS PLAN IS WELL WRITTEN AND WELL RESEARCHED. IT IS OBVIOUS THAT MUCH WORK AND INTEREST HAS BEEN EXPENDED. IT IS CLEAR THAT YOU HAD GOOD COMMUNITY INPUT IN YOUR FOCUS GROUPS. THE STAFF HAS DONE A GREAT JOB OF ORGANIZING AND WRITING THIS IN A CLEAR MANNER. THREE CHEERS FOR YOU!!!

1) Thank you for including the Parent Coalition in your Plan. Would you consider adding the following to page 20, PC/PT? Monthly meetings are held; monthly news and frequent emails of information, events and legislative alerts. Parent Training will respond to the public's suggestion of pertinent trainings.

2) I wanted to thank you for making this Plan so accessible and family friendly. Thank you for holding the local meetings. People really liked that. Thank you for asking for input from the families. These families know that the County cares about their opinions. I think this is very healthy. There is almost no input to regional issues.

3) Page 46 – as I understand it, it is more difficult for a person 18 years old to sign up for SSI if they have a work history. Caution here on last bullet.

4) Page 47 - under Strategies to Fund Supports for All Age Groups: Would you consider adding: Continue to teach people with DD and their family members about advocating for services and funding.

5) Page 47 - next to last bullet. Inequity of service system. This is really important when you talk to a group of families. The inequity of the DD system is intensifying. How will the County lead the way to figure this out for all people?

6) Page 42 – Issue the developmental disabilities support system is complex and continuously changing. Would you please consider adding Parent Coalition and Parent Training here and the benefits of being on our contact lists?

7) Page 32 – it is stated that funding for Transition students has happened since 1990 except for the year 2002. This is incorrect, it was 2003 that had no funding.

8) I believe unserved adults have given up. We don't even know where many of them are. There is no follow-up after vendors do not replace.

10) I believe that Aging issues are so important. I read focus groups, but saw little in the Plan that addresses them specifically.

11) I would suggest that there should be a staff contact list available for interested persons. Name email, phone and JOB responsibilities.

12) Page 51 – Thank you for the pledge to continue Family Support grants. Through much feedback, I believe this is a great support to families and people with DD.

This is an opportunity for me to thank the KCDDD staff for the difference they have made in the persons whom they have supported in employment.

I must say, that when our son was born 36 years ago, we were given no encouragement about the future. It was scary and daunting for years. Once we realized our son's abilities, we refocused on an unknown future of hope.

It is one of the most fortunate things in our family's life that we moved back to this area in 1986. Dan received the best education in his school experience in the Lake Washington School District. He then entered the adult service system.

Yes, I was interested in being a part of the advocacy movement. Yes, I showed up at board meetings and asked questions. But also, the County valued this parental input and responded with a Task Force for the Unserved and with the LOGIC project. KCDDD has been a mentor for parents ever since those days in 1989. This is no small accomplishment.

The supports you have managed through the years were a life changing opportunity for our son. The attention which your office continued to give to the blossoming of the employment arena is phenomenal. You were a huge part of giving our son a "typical life." Parent and school and medicine were partners. You had the vision of the civil rights of people being in ordinary places, doing ordinary good things. You utilized the power of good government to make this happen for many. Now, let's work on having this wonderful service available to more people!

You have also lead the way to give funding from your millage dollars to support people with DD and their families. This has been carefully planned. This funding has touched many people's lives in a myriad of ways.

And finally, the cooperative environment that exists presently between KCDDD and Region IV DDD is a pleasure to experience. Thank you for making the governments mesh together for good outcomes for individuals with DD. Thank you so much.

Comment 11:

On Page 42, under the issue that the DD support system is complex and continuously, I would like to see the Parent Coalition and Parent Training program mentioned. In both programs we are continually reaching out to families to bring them the most up- to-date information that we can find on issues that span the lifetime of the person with a disability and their family. We collaborate with other programs in order to reach as many people as we can and constantly search for new families to bring them needed information.

On Page 50, 51, and 52, I am pleased to see the points regarding bringing information to families and collaborate with the County to bring Transition to Adult Services" trainings to families. I would like to see the Parent Training program and the Parent Coalition identified in the goal to make information available to all families and the objective to increase awareness of the need to promote and actively support inclusion of people with developmental disabilities in their communities.

I strongly believe that through the Parent Coalition and Parent Training programs we touch many families and bring information to them that changes their lives. I have concern that by not identifying this specifically we might lose this resource to families.

As the mother of a 32 year old young man with significant disabilities who works in the community in individual employment, I support the work that the county does to recognize all person's abilities and their right to work in the community in an integrated setting. I fully realize that this might not have happened in a county or a state that did not have this belief. I also have another daughter that is in DD without the funding for employment that will need support in her work and I have great worries about this need for her.