



DISABILITY
LAW
CENTER

Utah's Protection and Advocacy Agency

Listen and Learn

The needs of people with disabilities in Utah

A report to the community from the Disability Law Center
June 2005

The Disability Law Center

The Disability Law Center (DLC) is the only statewide disability agency in Utah which provides self advocacy assistance, legal services, disability rights education and public policy advocacy. As the private, not-for-profit entity designated by the Governor to administer the federal protection and advocacy system, the DLC has broad statutory powers to safeguard the rights of people with disabilities.

We envision a just society where all people are treated with equity, dignity, and respect.

Our mission is to enforce and strengthen laws that protect the opportunities, choices and legal rights of people with disabilities in Utah.

The DLC provides free services to people with disabilities throughout Utah.

In the summer of 2004 through the spring of 2005 we held a ‘Listen and Learn’ tour (L & L), traveling the state to meet with a total of 278 individuals in 26 counties. We also conducted an extensive needs assessment and barriers survey, a focus group with Spanish speaking individuals with disabilities and surveyed 398 polling places in all 29 counties on Election Day 2004.

This report details the findings of these needs assessment activities. We hope this information will inform the public, clients, providers and advocates about the issues of the state’s 376,000 citizens with disabilities.

A consumer-driven organization

The DLC prides itself on being a consumer driven organization. Our agency seeks continuous feedback from the community about the needs of persons with disabilities, and develops programs and services that seek to address those needs. There are many ways the DLC seeks to ensure that its services and programs meet the ever-changing needs of our state’s citizens with disabilities.

These include a seventeen member Board of Trustees, 76% of whom are a person with a disability or the parent of a child with disabilities. The DLC also has the input of a Consumer Advisory Council, which specifically addresses the complex issues of mental health care and services in Utah.

The DLC holds a series of focus groups in specific populations each summer. In recent years past we have focused on ethnic minority communities, and disability-specific groups, such as persons who are deaf or have a Traumatic Brain Injury (TBI).

This year's needs assessment

Each year the DLC reviews its priorities and sets new goals or modifies goals for the coming year using the input gathered in the needs assessment process. Revisions to the plan are reviewed and further refined by the Board. We will jointly develop a new plan in 2006 to guide our work through 2009. This needs assessment report is an invaluable tool to the Board and staff committee charged with developing this plan.

This report summarizes findings from the FY 05 needs assessment. We anticipate that the results of the Listen and Learn tour may promote more substantive changes in the DLC's programs and services, especially in the areas of consumer councils, rural outreach, training and rural systems change advocacy. This report includes:

- 1)** Results of the Listen and Learn Tour, and polling place accessibility survey
- 2)** Results of the annual survey for FY 05, which focused on barriers and needs
- 3)** Results of a Spanish language focus group
- 4)** Results of our annual survey for FY 04, which focused on rural programs and services

The Needs of Citizens with Disabilities in Rural Utah

People with disabilities in rural communities face barriers and problems that seem insurmountable and complicated compared to people in the urban areas. These barriers are further compounded by underlying issues of poverty, isolation, distance and stigma.

Major findings

- People with disabilities in rural Utah suffer from very limited, inadequate or poor quality and poorly coordinated services for persons. This was the major concern of nearly all who participated in the L & L.
- Cuts to mental health services and Medicaid services are having a profound impact on the lives and health of rural citizens with disabilities.
- The state's under-funded public school system has an even greater impact on children with disabilities, who go without needed services and opportunities.
- The lack of rural public transportation severely reduces the independence of people with disabilities and their ability to receive services.
- Accessibility into buildings, post offices, roads and other public places and roads are of great frustration and a continuing barrier to full participation in society.
- Discrimination continues to be felt by rural Utahns with disabilities, notably in education, housing, employment and certain services.
- Stigma and intolerance were reported at even higher levels by people with mental health issues.
- Rural Utahns with disabilities face enormous barriers to employment. The overall lack of employment opportunities in rural areas is compounded by prejudice and a lack of educational opportunities.
- A lack of collaboration between existing service agencies makes access to services even more difficult. The waiting list for DSPD has a heavy impact on these families.
- The lack of resources extends to information about disability-based rights and too-limited legal representation on a broad range of matters, like guardianships.

- Individuals want the DLC to provide self-advocacy support and training for all major rights areas, especially special education and the Individualized Education Plan (IEP) process. There is a clear need for more general information about the DLC and its services.
- Voters with disabilities are hopeful that the Help American Vote Act will give them true access to this foundation of our democracy.

County by county results

The following are the major themes identified in each of the counties.

Beaver County – Minersville

Population: 6,059
 Residents with disabilities (% and n): 16% – 963

Issues

- *Lack of information:* Consumers do not know what services are available or who to call to get information. For example, a participant raised an issue on behalf of a mother with an adult child who is in need of assistive devices. Neither the participant nor the mother was aware that Red Rock ILC serves their community.
- *Transition services:* Participants reported that there are no appropriate transition services for people with disabilities who have completed their education. This is a change from past years when the district had a “highly functioning” multi-disciplinary team. When the school board membership and administrator changed, the transition services team disbanded due to lack of support.
- *Special education:* Participants felt that the school board and faculty are ignorant of their obligations under IDEA and 504. A group of parents organized by the local Family Council called the DLC for assistance last year got “great advice” from an attorney on how to approach the school board about their issues. The school board got angry with them and “retaliated.” Specific incidents of retaliation included refusing to let the Family Council hold meetings at the school and not rehiring a special education teaching assistant who was one of the organizers of the meetings. The group is currently suing the school district for copies of special education budgets which the school refused to give them under GRAMA and the Freedom of Information Act. It was later revealed that the school was not keeping record of special education funds. Participants also believed that the special education classes at the high school are overcrowded, that the district is not fulfilling its obligation to have a degreed professional special education teacher, and one person is having problems with the high school because it failed to recognize an outside provider’s referral for her son’s need for special education services. One person also believed that current special education aides at the schools are under qualified to provide the level of care needed for some students with severe behavioral and physical needs. She acknowledged that locally there is not enough money to hire people with the level of training needed.
- *Employment:* Participants reported that there are few businesses that are willing to hire people with disabilities. Participants believed that this was both due to discriminatory hiring practices and an overall poor job market as most of the jobs

Participants reported only a few businesses are willing to hire people with disabilities.

available in the area are with fast food chains. One participant reported that the local pool refused to hire an individual for a life guard position because of his ADD, despite his having medications that controlled his symptoms. Another individual reported having problems finding a job in his area of interest, auto repairs, because of his disability despite his having received vocational training in that area.

- *Accessibility:* Participants reported that schools, businesses, post office, and libraries are inaccessible. The hospital was reported as only being accessible through the emergency room.

Ideas to improve services

- Advocate for the development of a community resource center to provide information and day program services to people with disabilities.
- School board and faculty need training on transition services/obligations. Hold trainings with local service providers to make them aware of their legal obligations.
- Rights trainings for people with disabilities, especially special education.
- Publish a referral list of services available in the county in the county paper.

Box Elder County – Brigham City

Population: 43,397
Residents with disabilities (% and n): 14% – 5,871

“My daughter was told she couldn’t be in the school concert.”

Issues

- *Employment:* The main issues of concern in Brigham City are a lack of employment opportunities for persons with disabilities and the lack of an accessible transit system. Participants also reported that the local Vocational Rehabilitation office is “difficult to work with.”
- *Special Education:* The community reported that teachers in the school district require training. One participant’s daughter was not allowed to perform in a concert and there was a general sense that the schools could do a better job of increasing sensitivity both of teachers and students. The school bathrooms are not accessible to children with disabilities.
- *Health Care:* Medical professionals are “not sensitive enough – [they] need to lower examination tables, and dentist chairs are too high” and the cost of prescription medicines through Medicaid is prohibitive.

Ideas to improve services

- Increase outreach to rural areas to gain local trust.
- Advocate to make Voc Rehab work with kids in transition.

Cache County – Logan

Population: 91,208
Residents with disabilities (% and n): 10% – 8,974

“We need more affordable housing.”

Issues

- *Housing:* Finding affordable housing and issues of housing discrimination were important issues.
- *Special Education:* Support and services within schools were the main issues reported in Cache County. Participants reported that teachers and administrators need more training about the law, the ADA, and special education needs in the community. Participants requested that the DLC monitor the testing systems and file a class action suit against the district. Participants also reported that districts should have self-assessment or random assessments on how they are doing. One parent also suggested that the school district should be trained on how to use augmentative devices and other forms of telecommunication. One participant reported that the school asked a child with visual impairments to “leave.”
- *Transition services* are also lacking: One participant noted that there are “no transition services,” no funding to assist people with disabilities once they leave the special education program, nor services to assist them to transition to vocational training and employment.
- *Access:* There were specific issues reported by a person with a hearing impairment. For example, funeral parlors have very poor or no listening devices and few services provide interpretive services for people who are hearing impaired.

Ideas to improve services

- Hold rights training on K – 12 education issues, mental health issues, and senior citizen issues.
- Advocates are needed to attend IEP meetings “so parents feel more confident.”
- Provide parents with self advocacy training regarding special education services and about the rights of parents of children with disabilities.

Carbon County – Price

Population: 19,703
Residents with disabilities (% and n): 21% – 4,230

Issues

- *Services and Disability:* Carbon county residents saw many systemic problems with disability services, welfare, and workers compensation: “They all set you up to fail. You can’t get services on your own.” There is an overall lack of services in the region — DSPD, health care, mental health, Medicaid, food stamps, housing, etc. People expressed frustration with rural services in general. There are large numbers of persons with disabilities in Carbon County, more *per capita* than in larger, better funded areas. But participants feel the legislature looks only at the population count and not the needs of the community. Organizations that provide education/services are all on the Wasatch front, and people feel cut out of the political process.
- *SSI:* Social Security is a big issue in this mining town. People had problems with overpayments, getting back to work with cash benefits, and medical benefits.
- *Health Care:* Medicaid is also a concern. People had trouble following the Medicaid cutbacks and felt they could not get the care and services they needed. There were

“The system sets you up to keep you below poverty.”

changes in the medications program without notice and people were given misinformation by Medicaid. The co-pay on Medicaid is too high for medications, causing one woman to go without certain medications. The high co-pays on hospital stays are also a barrier.

- *Mental health services* are also affected by the cut backs. There was a loss of treatment staff, and the local mental health center sent out a letter that the rates were increasing for private pay clients due to funding cuts. Some people in attendance were now paying for services received at the Clubhouses, which they cannot afford. Stigma and intolerance — especially towards people with mental illness — is worse in rural areas.
- *Children* with emotional or physical disabilities also face difficulties. “The parents go to get services then the services are gone and the parents wait and wait and the kid’s health is affected. There is no notice when services change so you cannot plan.” They reported inequitable treatment between kids with disabilities and those who are in foster care.
- *Transportation*: There is no public transportation so people have had to turn down jobs due to lack of transportation.
- *DCFS*: People think that families below the poverty line are targeted by DCFS and children are taken out of the home for alleged abuse and neglect. The problem is compounded by a lack of lawyers in the area who will take these cases.
- *Employment*: Discrimination in the area of employment is an issue. One man reported that his applications would “come up missing” and that he was told he couldn’t work in some buildings because there were no lifts for the stairs. Many buildings are inaccessible. He now works at Wal-Mart and has his own business. One person was complimentary of VR, who helped him start his own business. He suggests VR work to recruit jobs into the community instead of referring people to move into a new community.
- *Complexity of the system*: People are penalized for not understanding the system and how it works instead of being given information. When problems exist — even when the state is responsible — they put the responsibility back in families lap. The lack of education about services includes Benefit Planning, Outreach and Assistance, Ticket to Work, and Medicaid Buy In. Participants feel they may be getting an inaccurate version by providers. People in the middle range of income fall between the cracks to obtain services. They have too much money to qualify for many/most programs and still not enough money to pay for the services out of personal funds.
- *Rights education*: People do not know their legal rights, especially regarding systems such as Medicaid, DCFS, Social Security, Workers’ Compensation.
- *Special Education*: Schools are using the lack of funds as an excuse for not complying with IEPs, IDEA, or § 504. It is hard to implement inclusion for kids with developmental disabilities, who are often denied IEPs even though they have documented disabilities. These children may end up in self-contained classrooms or even self-contained schools. There was a claim of retaliation by the educational system: “When families become empowered, the agencies feel challenged.”
- *Advocacy*: The “good ol’ boy” network inhibits advocacy, and has a “territorial control” of the area.
- *No attorneys* in the area are willing to work with people with disabilities.

Ideas to improve services

- Have a database with consumers' rights for the different agencies in "normal English, not legalese."
- Provide training on legal rights.
- Help coordinate a coalition among different agencies, groups serving consumers, and/or consumers to help consumers organize themselves to better advocate for themselves.
- Give people in rural Utah a voice on advisory councils/boards, etc. and create a dialogue with people in the rural areas to help them identify problems.

Daggett – Manila

Population: 905
Residents with disabilities (% and n): 15% – 139

Issues

"The closest services are 70 miles away."

- *Services:* The biggest barriers/problems the individual faced were a lack of services. Since services are based on population and Daggett is so small, there are no services. The closest services are 70 miles away. There are no VR services in Daggett County and limited employment opportunities.
- *Agency Criteria:* Different agencies have different criteria for services. This person is ineligible for SSDI because he "should be able to work" and therefore should be on unemployment if he isn't, but is ineligible for unemployment because the doctor told him he cannot work and unemployment says he should be on SSDI.

Ideas to improve services

- Provide more information on the rights of people with disabilities.
- Take a leadership role in bringing services to Daggett.

Davis

Population: 244,840
Residents with disabilities (% and n): 11% – 26,939

The Disability Law Center has held specific focus group meetings in the urban area for years, so no meetings were held in Davis or Salt Lake County.

Duchesne – held in Vernal

Population: 14,709
Residents with disabilities (% and n): 17% – 2,439

“People we work with need a different perspective, they need to be more humble.”

On the advice of the local contact the two counties of Uintah and Duchesne were combined and one community meeting was held.

Issues

- *Stigma and intolerance* ranked high in this area. As a result, people with disabilities are not treated with respect and understanding and are alienated. Others think people with disabilities are criminals. “If I say hi, no one says hi back.” The “community requires patience.” “People we work with need a different perspective, they need to be more humble.” The public needs to be patient with people with disabilities, too. There is also a sense that people with disabilities discriminate against other people with disabilities. The Special Olympics were cancelled, disappointing the children and parents. People with disabilities need to learn to speak up for themselves and “normal” people need to be educated. “People here are very afraid of labels.”
- *Rural concerns:* Living in a small community creates specific problems. People get blackballed from services. All the agencies talk to each other with no regard to confidentiality. “People are scared to speak out because they are worried that if one agency person does not like you, no one will.”
- *Employment:* There are few if any jobs in the area and employment discrimination is an issue. “If people with disabilities are upfront and honest about disability then they will get a non-renewal notice from their job.” Employment laws should be improved. Transition services are also an issue and “kids need jobs.”
- *NIMBY:* The DLC should educate the public about housing rights and NIMBY-ism. There was an issue with construction of a group home, but the group home won.
- *Transportation* is a huge problem in this rural area. Many people live way out of town.

Ideas to improve services

- Disability awareness education needed in schools, scouts, and state.
- Educate employers and employees about people with disabilities in the work place.

Emery County – Green River

Population: 10,609
Residents with disabilities (% and n): 16% – 1,648

Issues

- *Special Education:* The biggest barriers/problems facing people with disabilities were in the area of special education. People feel the Emery County school district does not comply with IDEA.

“People can’t get out; there is no place to go.”

- *DCFS* issues were also raised in this community. Again, people feel children are being taken out of the home without reason and they have problems fighting the state.
- *Services*: In general, people have a hard time getting services here. One bright light is Voc Rehab, which is “quite good.” The lack of services includes disability related services and legal services generally, including public defender, and poverty and family legal services. This community faces the common problems in rural areas related to distance, travel, and a lack of local options.
- *Access*: Physical accessibility is an issue and it is worse for adults with disabilities: “they can’t get out; there is no place to go.”
- *Mental health*: Problems with substance abuse, mental illness, and suicide prevail.
- *Religious discrimination*: Some felt they faced discrimination based on religion rather than disability. If you are “one of the ‘good families’ you get services.” The discrimination is poverty related.

Ideas to improve services

- Education/information outreach about the needs of people with disabilities and the ADA laws was very important.
- Provide bi-lingual services.

Emery County – Castledale

Population: 10,609
Residents with disabilities (% and n): 16% – 1,648

Issues

- *Services*: Misunderstanding by professionals and poor services by local agencies were the biggest concerns in Castledale. Agencies “don’t want training and don’t want to have to understand.” In-home support services for families of people with mental disabilities are limited, as compared to the services available to persons with physical disabilities.
- *Transportation*: Participants reported that distance to services is also a concern, especially without a local transportation service.
- *Prejudice*: Participants reported that prejudices against people with disabilities are prevalent, with the exception of mental retardation, which is “received much better because you can see the disability.” One individual felt that most of the discrimination comes not from the community but from the agencies designed to help people. She told the story of a child who was not allowed to play ball by the Recreation department.
- *Rural issues*: Many of the concerns facing these participants had to do with living in a small, rural area where “everyone knows everyone else’s business.” One woman spoke of the repercussions she felt when she stood up for her rights and then “had to go to baseball games with these same people.” Another commented, “Kids at school don’t want people to know they are involved with agencies. They see agency people in the halls and duck their heads so they won’t talk to them.” Stigma is especially tough in junior high.

“Professionals want to do things in 1970’s way – not the 2000’s way.”

- *DCFS:* Participants spoke of calls being made to DCFS before people know what is really going on. They feel the DCFS process alienates the extended family.
- *Employment:* Vocational Rehabilitation services were reported as lacking. One person's counselor turned down his business plan twice, kept sending them back for more information and "acted like he did not want to help." The head of VR suggested the individual "go volunteer somewhere," when the person really wanted a job.
- *Special education* also is a concern. One parent said a counselor put her daughter into a resource classroom, because the teacher did not understand her. "Teachers need to understand children with disabilities." Participants reported that the Parent Center, which is funded to do special education self advocacy training, "won't come to Castle Dale and only serves parents in Price."

Ideas to improve services

- Provide self-advocacy training and support, especially to parents on special education as "the school districts don't want parents to know about IEPs" and participants did not think it would do any good to try to train staff.
- Help people when applying for social security.

Garfield County – Panquitch

Population: 4,724
 Residents with disabilities (% and n) 13% – 630

Issues

- *Transportation:* The biggest problem cited is lack of available public transportation services. The county is large with three distinct areas (Panguitch, Tropic, and Enterprise) and no way to get from one area to the other without self-transportation.
- *Employment:* People with disabilities face very limited job opportunities in the county, lack a public means to travel to access any jobs, and face the additional burden of competing for very limited and seasonal in nature positions.
- *DSPD:* Participants reported a need for increased DSPD services in the county. They suggest, more people be found eligible for services and request an increase in respite care for families already covered by DSPD.
- *Mental Health:* Mental health services were reported as "ok," with South West Center (but no clubhouse) and Frontier for Families. LDS Church Services also come to the area for social service needs and mental health support.
- *Lack of services:* Families with special needs family members, at times, decide to leave the county and move to more urban areas where additional services are available. There are no group home living situations in Garfield County so people often live with family. If an individual needs additional services, the entire family tends to re-locate. One observation made was that Family-to-Family services in the area would be better if the group was more active in the community. One person said his experience with services for his granddaughter have been exceptional and used that as an example to describe Garfield County as a place where people with disabilities are well treated.

"If an individual needs additional services, the entire family tends to re-locate."

- *Education and health care:* Participants described education services and access to health services as “good.” One person asked why insurance companies do not pay for hearing aids. “How can they make huge TV’s for cheap, and not a cheap hearing aid?”
- *Accessibility:* Schools and county offices were reported as being accessible and much improved over a few years ago.
- *Service coordination among providers:* Participants pointed out a need for coordination between all available services, such as People First, DSPD, and Vocational Rehabilitation. Getting together people from all disability groups and people who rarely leave their homes together would also be very useful.

Ideas to improve services

- Educate the community of certain type of disabilities, such as ADHD and Bi-Polar Disorder.
- Create an information resource center or a link to a resource guide for information on disabilities.
- Help find Respite Care. “We have to go to Cedar City for respite, my child comes home ill. It’s hard to find someone who can deal with the oxygen tanks and tube feeding, care center here is not state approved.”

Grand – Moab

Population: 9,633
 Residents with disabilities (% and n): 15 % – 1,488

Issues

- *Physical Accessibility:* The group felt that public officials are not aware of the physical accessibility requirements for public services, programs, curb cuts, etc. Crossing signals don’t give people with mobility impairments enough time to cross intersections. Crossing signal buttons for pedestrians are too high. Public meetings are not always accessible.
- *Public accommodations:* Many businesses don’t have ramps, many new business buildings aren’t built with ramps or accessible bathrooms or entrances. Public recreational trails are also inaccessible for wheelchairs because they have things like speed bump barriers put in place to discourage bikers from using paths meant for walking — but that makes them inaccessible to people using wheelchairs.
- *Transportation:* This is a significant issue in Moab. Public transportation does not exist, so people with mobility impairments are isolated. The only available accessible transportation is on the Senior Citizen Center van, which is sometimes available for others with mobility impairments. The only other available accessible transportation is for medical care. The problem here, as in the majority of rural areas, is that a municipality or county does not have to have a public transportation system. They are only required to make their public system accessible. Since Moab apparently does not have a public transportation system there is no legal advocacy to address this important issue. We would want to investigate what public transportation system, if any, exists in Moab.

One mother described a self-contained class “being held in a closet.”

- *Social Security Disability Benefits:* A few participants spoke of difficulty becoming eligible for benefits, especially the lengthy application process. One speaker felt that if you request that your case be expedited, or complain about the length of time, you get bumped to the bottom of the list. While there was no discussion about the lack of availability of formal representation in the process, we suspect that this is a need.
- *Mental Health Services:* Of the 15 participants at least four represented primary or secondary consumers of mental health services. They complained about the lack of adequate services for both children and adults. No one was criticizing Four Corners Mental Health, but pointed out that it has only four therapists for Green River and Moab. Types of services that are not available include all services for kids; substance abuse; PTSD and other diagnoses; and children who have suffered sexual abuse. Because of federal and state cuts, Four Corners now only treats individuals on Medicaid or enrolled in CHIP, so little is available for others unless they have private insurance coverage. These cuts have meant that Four Corners Mental Health no longer provides services they previously provided on sliding scale fee for those marginally above poverty line. One participant spoke of the need for a residential program for individuals who have suffered sexual abuse as children and programs for young adults with substance abuse problems.
- *Transition Services:* The lack of appropriate transition services was identified not only for traditional special education services, but also children and adults with significant mental illness. There are not enough supported employment job opportunities. People with various mental disabilities need training in a wide range of activities, including ADL's, IADL's, recreation skills, and social skills.
- *Transitional Housing:* There is a need for more transitional housing for young adults with various disabilities who are ready to move from their family homes and establish independence.
- *Special Education:* Participants suggested that one of the most important things we can do in this area is training. Parents do not know what their rights are and are typically offered less than what their children are entitled to. Participants described behavioral interventions used that fall way beyond the limits of the LRBI. One parent felt that strong advocacy can result in retribution.
- *Medical Services:* There appears to be a lack of occupational therapists (OT) available in the area. The one OT is under contract with the school district, but is not available for many patients outside this contract. One mother said that her child did not receive anywhere near as much OT in Moab schools than the child previously received in California. The majority of medical services are remote. Grand Junction, Colorado is the closest place to receive many services.
- *Guardianship:* The community needs more information on guardianship issues. The guardianship process is cost prohibitive (attorney involvement) and parents need information about how they could do it on their own.
- *Stigma:* Participants spoke of attitudinal barriers in the community that are long standing – passed down from generation to generation, and involve rejection of people asserting rights. Public needs greater awareness of rights and needs of people with disabilities.

Ideas to improve services

- Form a local disability advocacy group to create a resource for disability advocacy — would need training, assistance in developing advocacy strategies.

- Improve use of local media, including the newspaper, media interviews in advance of meetings, and a “Roller ad” on TV.

Iron County – Cedar City

Population: 34, 448
 Residents with disabilities (% and n): 12% – 4,123

Issues

- *Closure of our office:* As anticipated, participants focused on the closure of the Cedar City office.
- *Other issues* of concern to participants were ADA building compliance and special education issues. Local residents feel that it is nothing particularly specific regarding accessing services. Parent IEP training came up.

“Our schools need to be watched all the time.”

Ideas to improve services

- There were many comments about the need to attend IEP meetings.

Juab County – Nephi

Population: 8,489
 Residents with disabilities (% and n): 16% – 1,319

Issues

- *Mental Health services:* As a result of the changes to Medicaid, Central Utah Counseling has had to end services to non-Medicaid low income clients. They report many individuals have lost service. As a result of limited availability of counselors in the region, people have to drive to Provo for services and agencies have to turn away a lot of people. However, the Central Utah Mental Health has transformed some motels into housing for clients, which has increased community awareness and tolerance of individuals with mental illness.
- *Lack of DSPD Services:* Those in attendance feel that services are much richer in Utah County than in Juab. “Families lose a lot of services when they move to Juab County.” Families also report “a lot of disparity between families and the services they receive.” Families feel this is very case worker dependent.
- *Disparity in use of Housing vouchers:* If you have a housing voucher from Utah County – you can use it in Juab County, but the reverse is not true. If you have a housing voucher from Juab County – it is not good in Utah County.
- *Education:* Juab County “has never had a due process hearing. We pride ourselves on working issues out informally.” All students in the district spend some time in a regular classroom.

There is “a lot of disparity between families and the services they receive.”

- *Community-wide problems:* The challenges faced by people with disabilities are shared by the majority of people living in the region. There is a lack of housing and jobs for everyone.
- *Employment:* Access to Vocational Rehabilitation Services is difficult since Rehab only visits one day a week and “there is a lot of turnover.” Employers need more training on working with people with disabilities, and employees need more training options (supported employment).

Ideas to improve services

- Participants felt that the Family to Family network needs more support and training. There is a good ADHD day camp, and this would be a great opportunity for a workshop for parents.

Kane County – Kanab

Population: 6,058
 Residents with disabilities (% and n): 16% – 954

Issues

- *Special Education:* Kanab is “not so bad” but issues are mostly difficult for kids with disabilities that are often mistaken for disciplinary problems (mental illness, behavior disorders, and learning disabilities). Area parents often think that receipt of special education will stigmatize their children so they refuse or don’t ask for services. Children then deteriorate. Kids with subtle disabilities are at more risk for abuse from classmates or for not being observed as in need of services. The local school has recently enrolled five new children in kindergarten that are diagnosed with autism. These children are usually mainstreamed in the school system.
- *Mental health services* are lacking: The community mental health provider is under funded so it is hard to retain staff, especially in the school setting. Currently there is only one APRN and one therapist on staff. They cover a large area and their participation in regional meetings and high, spread out caseload results in appointment cancellations or their presence in the area only every 6-7 weeks. Kanab currently has one private psychologist and one private therapist available for therapy services. The South West Center is in need of a psychiatrist but will not use the local one. Because of this, patients have to wait over a month to see a psychiatrist. Psychiatrists are not approved by Medicaid unless South West Center approves them and they will not approve the local psychiatrist.
- *Little collaboration between existing agencies:* Limited resources divided between competing service providers results in wasteful duplication of services and not enough attention paid to service gaps. Increased collaboration is needed between agencies to share resources/government funds.
- *Voting:* The County Clerk is very dedicated to ensuring that all polling places are ADA compliant.
- *Transportation:* There is no bus or cab service within the county. There is a Senior Citizen bus that will transport seniors to St George. A Greyhound bus trip to St George costs \$50 round trip. New Frontiers for Families and Turn Services are

“There needs to be increased collaboration between agencies to share resources and funds.”

located within the county and will occasionally provide transportation to doctor appointments, but family and friends are the primary source of transportation.

- *DSPD*: A DSPD caseworker comes to town occasionally. She drives from Springdale which is over 100 miles away.
- *Health*: There are 2 dentist, 6 doctors, and 2 physical therapists that practice in the city. An Occupational Therapist and a Hearing Specialist come to town occasionally.
- *Housing*: There is one apartment building in the area that is ADA accessible *and* available to low income individuals. The county anticipates building another in the future.
- *Employment*: Employment for people with disabilities within the county is limited. Most people are employed by family businesses, farms or restaurants. No job training is available, although career counselors are available to people in high school. Participants listed major local employers they say do not hire people with disabilities.

Ideas to improve services

- Have training/education programs for parents about special education services to decrease stigmatization.
- More handouts in layman's terms to help with trainings, especially special education rights/laws.
- Advocate so the local swimming pool can be used by people with disabilities.

Millard County – Delta

Population: 12,424
Residents with disabilities (% and n): 15% - 1,879

Issues

- *Information on Self-Advocacy and Rights*: Families tend to be self-reliant or rely on church so there is resistance to asking for/using other services. There is also a reluctance to label selves as “disabled.” The combination of a self-sufficient attitude and stigma associated with having a disability results in consumers not knowing what resources/services are available.
- *Special Education and School Accessibility*: Schools, especially those in Delta, are slow to follow through on IEPs. (Fillmore is perceived as better.) The elementary school that was built about 10 years ago in Delta is not accessible; students with accessibility challenges must enter through the gymnasium.
- *Transition Services*: Local businesses refuse to hire people with disabilities and there are no alternative day programs for non seniors. Consequently, young adults with disabilities aren't working and “wander the streets” with no structured activity. A few individuals are sent to a senior center in Fillmore, and others are given passes to activities at the local high school including school dances and football games.
- *Employment and Job Discrimination*: Community Careers has a contract to provide direct on-the-job supervision but are not providing enough services in the Delta area. Consequently, the local WFS/VR office may lose potential employers due to lack of job supervision services. The city library in particular was cited by one participant who

“There is nothing for people who finished school but T.V.”

felt she was denied employment there based on her disability, despite having experience and a desire to work. Additional barriers to hiring include the fact that many of the business buildings in Delta are old and may not be accessible, with changes not readily achievable in many of these buildings. Additionally, local businesses are struggling to survive and compete against national chains and lack the resources to hire new employees. It was also felt that local employers are uninformed of the benefits of hiring people with disabilities.

- *Guardianship:* Families don't have information on guardianship process and rights. They also may not have the money to hire attorneys to adequately represent both the proposed ward and proposed guardian.

Ideas to improve services

- Flyers and mailers were suggested as the best ways to get information to consumers.
- Train employers on incentives for hiring people with disabilities at Delta Chamber of Commerce meeting.

Morgan County – Morgan

Population: 7,337
Residents with disabilities (% and n): 11% – 777

Issues

- *Transition:* There are no transition services available in Morgan itself. Vocational Rehabilitation wants consumers to go to Davis County for employment/transition services and will not send counselors to Morgan for planning meetings. Morgan residents who cannot live in Davis or cannot get transportation there “end up sitting around at home with nothing to do.” Families are too isolated from services and are unaware of how drastically programming changes once an individual transitions from children's programs to adult services. There is one bright note on the horizon — North Eastern Services will be operating a day program in Morgan soon, once they can get county approval. People are hopeful that this will provide needed day services in the area and that NES employees will be able to help with transition planning.
- *Transportation:* This is an underlying issue to many problems faced by people with disabilities statewide and in Morgan County. The lack of public transportation and the lack of personnel to help support an individual to travel to Davis County means few can receive needed services. The community is unwilling to increase taxes in order to get para-transit services in Morgan
- *DSPD Waiting List:* One person reported that her grown children have been on DSPD's waiting list for over 8 years and she feels that “honestly, they will never get services.” She felt that she would have to “throw her kids out on the street” to get off of the waiting list. The DSPD waiting list is the reason most people in need of services in Morgan have not received needed assistance. “People in Morgan do not want to participate in a grant program.”
- *VR/Employment:* Participants cited a need for VR to provide services for self-employment. In general, they expressed frustration with too much bureaucracy which overrides providing good service: specifically, a person is given a transition counselor

“My grown children have been on DSPD's waiting list for over 8 years.”

while in school, then is switched to a new counselor because they have graduated, despite the relationship that has been built. Employers in Morgan are willing to provide job coaching services but are unwilling to actually hire a person with a disability.

- *Medical Care:* One family stated that their physician refused to submit insurance reimbursements because Down's Syndrome "is not a qualifying condition." Doctors overall seem unaware of treating accompanying disabilities/conditions that result from Down's Syndrome.
- *Cultural Issues:* The community values self-reliance or help within the community and is unwilling to access programs/services outside of that community.
- *Architectural barriers and stereotypes* were the main barriers to people with disabilities, however, one participant feels "things are not all that bad up in Morgan" and that the school district in particular has improved.

Ideas to improve services

- Train parents on early intervention training, how to access services/programs and the difference between eligibility and entitlement.
- Have schools set-up some sort of system like CAP where the districts actually tell parents that they can call us if they have problems/questions.

Piute County – Junction

Population: 1,387
Residents with disabilities (% and n): 19% – 269

Although the DLC traveled to Junction for an L&L, it occurred the day of former President Reagan's funeral and was scheduled in a federal building which closed.

Rich County – Randolph and Garden City

Population: 1,979
Residents with disabilities (% and n): 13% – 248

"When a parent complains the school district usually states they do not have enough money."

Issues

- Two providers from Logan attended this meeting from DSPD and Mental Health. The two DSPD case workers who came from Logan complained bitterly about the fact they had had to conduct in-house site visits more frequently than before.
- *Supports and Services:* The biggest barriers/problems facing people with disabilities was the lack of support and services to individuals providing care to persons with disabilities. Support and monitoring of care givers that provide Medicare and Medicaid services were also requested. The overall lack of information about rights and services in this rural area contributes.
- *Special Education:* Participants reported that IEPs are poorly developed. Many services, especially out of school programs, are only offered if every special education

child chooses to participate. When a parent complains, the school district usually states they do not have enough money to pay for the service. Parents are also concerned that “mainstreaming is not done well.” For example, special ed students are not offered an equivalent summer school in length and time to regular education students.

- *Transition:* Transition plans are not written. “The school district says they are too expensive.” Many kids between the ages of 18-22 sit at home and watch TV. Physical Therapy and Occupational Therapy are not available 3-6 months at school. There are no transition services for kids after they turn 18, and the high school graduates the students, knowing they cannot receive DSPD services until they are 22.
- *SSI:* Strong emphasis was put on the need for assistance with SSI/SSDI information and learning how to navigate through the forms and fill them out.
- *Discrimination:* There is discrimination based on economics. Prominent community figures receive the most services.

Ideas to improve services

- Pressure the State Departments of Health and Human Services for adequate services in this community. “Do not worry about creating more of an adversarial relationship because it cannot get any worse.”
- Since Rich Country was close to Wyoming, it was suggested that agencies increase interaction with those in Wyoming.
- Provide Special Education Rights Training and attending IEP meetings.
- Send alerts about how we can advocate for more funding.
- More face to face contact.

Salt Lake County

Population: 904, 331
Residents with disabilities (% and n): 14% – 131,045

The Disability Law Center has held focus groups in the urban area for years. The focus of this effort was off the Wasatch Front, so we did not hold the L & L meeting in Salt Lake County. This year the DLC conducted a focus group of non-English speaking persons with disabilities from the Hispanic / Latino community, which is summarized later in this report. The DLC participated in five ethnic community fairs to disseminate information about the DLC and its services. Other recent focus groups include persons with brain injury, and small group training on education, housing, employment, and access. If you would like a copy of these or any other past focus groups, please give us a call. We would be happy to share the results.

San Juan – Blanding

Population: 13,386
Residents with disabilities (% and n): 23% – 3,038

Issues

Participants reported confusion, and a lack of coordination between state and tribal public services.

- *Services:* The main problem is a lack of services. People reported a lack of access to services because of limited transportation, combined with a general lack of knowledge of services or the process for accessing services. One individual with a hearing impairment had to go to Salt Lake for sign language instruction. Parents receive no sign language training in San Juan, and are unable to speak with their child. Kids with developmental disabilities are at home all the time there is no respite or community activities. No physical therapy or occupational therapy is available in the area. Senior Citizens Center provides food for the elderly, but not for people with disabilities. Medical care is hard to receive on reservations.
- *Language barriers:* This was an issue for the Native Americans.
- *Service coordination between Native American and local services:* Participants reported confusion and a lack of coordination between state and tribal public services. Reports to tribal providers are not always acted upon.
- *Cultural issues:* Tribal members with disabilities, or family members with disabilities “lay low,” are self conscious, and have difficulty with talking about disabilities. The community does not acknowledge or accept people with disabilities. Advocates are seen as troublemakers.
- *Transportation* is a huge issue, particularly to Native Americans on the reservation. Many communities are very isolated.
- *Stigma:* People with mental illness are stereotyped and stigmatized, and tend to be known in community. One person told of how they were denied service in a restaurant.
- *Physical accessibility:* Many newer and older, public and private buildings are inaccessible, including restaurants, and businesses. The new park and park facility are inaccessible.
- *Employment:* There are no job opportunities in San Juan County, which has the highest unemployment rate in the state. An additional barrier is that many buildings where jobs are located are inaccessible. One person mentioned that their adult son is capable of working with a little training but can’t get a job. There is a belief that people with chronic mental illness will not be hired by private businesses. Short or long term job support is not available.

Ideas to improve services

- Increase awareness of DLC and other services.
- Be present in the area more frequently to learn more about the community. Given the isolation of the area, and the lack of transportation (especially on the reservation), agencies must go to each community to meet with various tribal councils individually, rather than have single site meetings.
- Conduct extensive training to the public about disability rights issues.

Sanpete – Ephraim

Population: 13,386
Residents with disabilities (% and n): 14% – 3,332

We were unable to hold a meeting in this county due to the lack of local contact and time constraints. We hope to visit in 2006.

Sevier – Richfield

Population: 18,961
Resident with disabilities (% and n): 15% – 2,860

Issues

- *Physical accessibility:* Participants suggested a disability advocate on the planning/building committees to make sure buildings meet code. For example, the library is not ADA compliant and apparently does not need to be complaint. The courthouse lacks an accessible county commissioner's office room. The county says that if the building is not accessible they "take the business to the car or to their home and accommodate them that way."
- *Social Security and Medicare:* An individual complained that she was not getting services in a timely fashion.
- *Housing:* Mobile homes are often the only affordable places available for rent, but rental agreements are often changed and rentals are not adequate. If the tenant complains, the landlord will often blackball him or her. A Headstart representative noted that housing is an important need for her parents.
- *Forest Service:* One man requested access for ATVs on all trails for people with disabilities especially for hunting.
- *Transportation:* There is no public transportation. The Senior Citizens have the vehicles but don't have the money to maintain the buses or pay employees who have special training to drive people with disabilities. The only type of help they have is volunteer assistants who have no training on people with disabilities.
- *Mental Health:* Native Americans residents need prevention, disability awareness, group and individual counseling directly focused to the Native American culture. Service providers need a liaison to the Native American culture.
- *Educational Trainings:* Participants requested teacher training so they know what they are dealing with and how to help and not hurt the students with TBI or DD / MR. There was a feeling that teachers don't want to be bothered. "They just want a pay check." There were many complaints about Snow College. A DSPD staff person pointed out the need for parent training on their rights and the rights of PWD. For example, they have the right to school till 22 years. "We need a parents and Special Education brochure."
- *Employment and Job Discrimination:* Two local grocery stores will not hire anyone who needs a job coach. They are blatantly discriminatory. "Richfield business people do not see any economic value in people with disabilities so they discriminate."
- One resident called from her home before the meeting and requested that we list her concerns. She is now in the waiting period for the SSDI and Medicare to kick in. She

is unable to go to the doctor because she cannot afford to travel — but she cannot get help if she does not go to the doctor.

Ideas to improve services

- Create a support group for the families, especially for the parents that are just going through the onset of a disability.

Summit County – Park City

Population: 31,103
Percent of people with disabilities: 8% – 2,395

Issues

- *Housing:* The Park City housing market makes affordable housing very difficult. No section 8 vouchers are available but there is low-income housing available. There is a waiting list and people with disabilities do not get preferential treatment. Not all low-income housing is ADA accessible. There are no group homes – people with disabilities either live independently or with families, this causes some affluent families to go outside the state for community – based placements.
- *Services:* Living in a rural area makes it difficult to find assistance and even to find transportation. Many times people have to go to Salt Lake to find the services they need, since there are few or no organizations with local branches. Most seniors do not live in Park City because cost of living too high; more live in Kamas. No center-based, day services available in the area, e.g. sheltered workshops, because there is no critical mass. Due to lack of community based services, some people have had to go into institutions. Early intervention services are all natural environment (i.e. in the home) instead of any center-based services, but they maintain good relationships with pediatricians in the area. Early intervention services are in private day care centers that will not take infants and toddlers with disabilities. Support services from churches are available, and, of course, affluent families in the area have more options.
- *Lack of information/Training:* Parents are frustrated that they get so little information from the school district or organizations, such as DSPD, to help their children. There is a need to teach parents of children with disabilities good self-advocacy skills without being too adversarial.
- *Employment:* One attendee was frustrated that so little had been done on his case with the DLC and that VR had not done anything to help him. He expressed concern about being able to find and keep employment. One issue of concern was not having special education students working in the community as a part of the transition services. SSI Ticket-to-Work is available in the area through Workforce Services, but the problem is getting private providers due to limited funding. Many young adults are exiting public school without much of a plan for post-school life and activities.
- *Education:* Kamas and Coalville are problem areas in the county, particularly for many 18-22 young adults, who are not getting services. People involved in education need some training to ensure a more seamless transition from school to post-school activities. It is difficult to get the Utah School for the Deaf & Blind (USDB) involved with students with disabilities after pre-school age (age 5 and older).

“Some people have to go to institutions because there is no alternative.”

- *Transportation:* Transportation in good — the county/Park City buses are accessible and there is a call based transportation service for the elderly. Kamas and Coalville are the only exceptions.
- *Cultural (Hispanic) issues:* Hispanic families are hesitant to access and advocate for services due to language barriers and fear of being undocumented. People without legal status get put on the bottom of the DSPD waiting list. Early Intervention gets good Hispanic referrals from WIC, and the People’s Health Center and Health Department could be a good source of referrals to disability service providers.
- *Other information:* Valley Mental Health is accessible and provides services on a sliding fee scale. VMH will not take infants and toddlers ages 0 -3, however Baby Watch now has a mental health component. Except for a group called “mothers of multiples” there is a lack of disability-specific groups in the area. Some effort has been made to organize a People First group. Some of the limitations on independence for people with disabilities are imposed on them by their families.
- *DSPD* is terminating eligibility for some people and it has become increasingly harder to be eligible for its services. Eligibility has become narrower for early intervention services.
- *Coordination:* A FACT program exists despite the funding from the state is no longer available. There seems to be good coordination amongst public service providers, good referrals to each other, although Voc Rehab may not be in the loop.

Ideas to improve services

- Parents in Kamas and Coalville request training in special education, especially transition services and rights.
- More outreach and building relationship with local contacts.
- Recommended that DLC try to attend some Family Council meetings.

Tooele – Tooele

Population: 44,157
 Residents with disabilities (% and n): 12% – 5,340

Issues

“I can’t afford to see a dentist since they cut it out.”

- *Health Care:* The biggest barriers facing people with disabilities were health care related — the overall cost of health care, the lack of dentists and doctors who will accept Medicaid/care, and the loss of services due to funding cuts. Discrimination in getting services as medical providers “looked down their nose” at Medicaid/care users.
- *Transportation* is an issue as Flextrans does not run to Salt Lake where most medical and other services are found. Others were not qualified to use the service, especially people with mental illness.
- *Access:* Some reported a lack of physical access to local shops.
- *Employment* discrimination is especially high among individuals who went through the local school system and are forever stigmatized and stereotyped. VR had only one counselor, who favors certain persons. No one knew of CAP. People also reported problems getting interpreters from Workforce Services when seeking a job.

- *Services:* Besides medical care, participants faced barriers getting DSPD services or even referrals from DSPD for non-waiting list help.

Ideas to improve services

- Need to organize to have “strength in numbers” such as a local Advisory Council,.
- More outreach so that the Tooele community understands the DLC and other services.
- Obtain more funding for Medicaid/care.

Uintah – Vernal

On the advice of the local contact, the two counties of Uintah and Duchesne were combined and one community meeting was organized in Vernal.

Population	25,926
Residents with disabilities (% and n):	17 % – 4,319

See report under Duchesne County.

Utah County – Provo

Population	377,411
Residents with disabilities (% and n):	10% – 38,248

When families move here from other states and show the district their IEP they laugh and say “we don’t do that here!”

Issues

- *Education:* Special education concerns included a lack of inclusion. One student had some time with regular peers in elementary school, but now has none in middle school. Participants felt that the school district refused to provide a one-on-one aide for their son, who remains isolated. Parents feel they are being punished for their advocacy. The district lacks an ASL interpreter. A parent reported that they and others are “being thrown out” of school for coming to school and interpreting themselves. One parent said the school district had provided an interpreter, but they stopped when the student was rude to the interpreters. They hired a private attorney, but feel that the DLC should have taken care of it. Other parents feel that teachers do not have the skills to “uplift” and teach special education students. They stated that relationships between teachers and students are often “punitive and demeaning.” Parents report that even when they get things included in the IEP (like daily reports), the schools still do not do the reports.
- *Retaliation:* Parents believe the more their kids are included the more they are accepted. These parents feel they know their rights, but feel the school districts over-ride their requests, and that the district minimizes their expertise regarding their children. They also expressed concern that their children will be retaliated against if they go to due process. Parents want a parent advocate in each school district that is aligned with the DLC.
- *Discrimination by the Legislature:* Parents believe their children are discriminated against by the legislature.

- *Abuse and Neglect:* CUCIL members reported being frustrated with conflicting referrals between the Ombudsman and the DLC.
- *Care Manager for IHC:* This system works well for families who have children with multiple special needs, provided they have IHC insurance.
- *Loss of Medicaid / DSPD Waiting List:* Attendees feel that the working poor can not cover their medical expenses. “The DSPD waiver is out of reach.” As a result, parents go bankrupt in order to provide for their children.
- *Family to Family Network:* These participants are very concerned that the Family to Family Network is “falling apart” since it was moved from DSPD to the Governor’s Council.

Ideas to improve services

- Several parents stressed the desire to have someone attend the IEP with them.
- CUCIL would like to have one parent trained in each district to help parents with the IEP process but feel they need training to do so. They would also like to be able to “use the DLC’s name for more leverage.”

Wasatch County – Heber City

Population: 16,200
 Residents with disabilities (% and n): 12% – 1,892

Issues

- *Accessibility:* Participants said that many old buildings and sidewalks are inaccessible to people with disabilities, and the violation of the use of accessible parking places is not always enforced.
- *Employment:* Participants identified a lack of jobs in the area for everyone, but they emphasized that it is especially hard for people with disabilities to find work. Most of the employment opportunities are in Summit County, and most people with disabilities do not have a form of transportation. Although employers are not familiar with employment programs for people with disabilities, the participants do not believe employers are discriminating against people with disabilities.
- *Lack of Transportation:* No mass transit opportunities are available in the area, including between Heber City and Midway. Participants identified transportation as the biggest barrier to full participation in day-to-day living in the community.
- *Recreation:* Participants indicated that there are no recreation services for people with disabilities in Heber. What is offered is limited to young adults who are members of the LDS church or people who can afford to participate in privately run National Ability Center programs. Lack of transportation was again mentioned as a barrier to participation in recreational opportunities.
- *Special Education and transition:* Participants identified a need to improve school buses by ensuring accessible buses with wheelchair lifts are available – especially for field trips. In addition, transition plans do not include support for kids to find paying jobs when they graduate. This service is needed. Finally, the participants noted the school system badly needs a speech therapist.
- *Mental health services:* Participants stated there are never enough mental health services available. They highlighted a need for social skills classes and therapists with expertise with sex offenders and crime victims.

“The people who are most in need of services are not receiving them. They are just waiting.”

- *DSPD waiting list:* Participants were very unhappy about the DSPD waiting list. Five years ago DSPD funding was almost automatic for families with young adults with disabilities. Since DSPD went to a state-wide listing system, the waiting list continues to grow. “The people who are most in need of services are not receiving them. They are just waiting.” Many families in rural areas like Heber are forced to migrate to larger urban areas to ensure services.
- *Ethnic outreach:* Service providers expressed how difficult it is for the Hispanic community to feel comfortable accessing services.
- *Housing:* Housing in Heber City is very expensive and there are little to no housing opportunities for low income people with disabilities.
- *Economic Development:* Participants hoped that Heber’s growth will improve the quality of life for people with disabilities in the area.

Ideas to improve services

- Create a local advocacy group to help bring awareness to the community through discussions, trainings on access and rights, etc., and assist advocates in the community with advocacy and legal issues.

Washington County – St George

Population: 95,590
 Residents with disabilities (% and n): 14% – 13,688

Issues

- *DLC level of service to rural/southern Utah:* One participant was concerned that with the closing of the Cedar City office there will no longer be “personal response to issues.” He described a general fear for Southern Utah residents, (the Dixie issue) “no one in Salt Lake City knows we’re here.”
- *Accessibility issues* were key in several communities. For example, in LaVerkin sidewalks are not maintained, and there are not enough traffic lights or cross walks. Military bases are not accessible and claim that they do not have to be ADA compliant. Low-income housing in St George is often inaccessible.
- *Housing Discrimination:* One participant who lives in low-income housing that his rent has been raised five times in the last six months, and it’s becoming financially impossible for him to live there.
- *Finding affordable legal representation* for people with disabilities: One participant asked about DLC’s ability to provide legal representation in personal injury claims. He felt the DLC should be more open to doing this kind of work as it is financially impossible for people with disabilities to find legal representation from the private bar.
- *Special Education:* Red Rock ILC gets a lot of complaints about the school district. One mother of a deaf child with mental retardation described her personal experience. If her son’s interpreter cannot attend school with him the school refuses to get a substitute and often tells her that if she can’t come with him to translate, then she should keep her son at home for the day. When she tried to get an interpreter provided in the IEP, she was refused and was told, “If we put it on the IEP we would have to comply.” She used to have to provide her own transportation to drive him to St George from Hurricane until she decided to mainstream him.

“If my son’s interpreter cannot attend school with him, they tell me to keep him home.”

- *Transportation:* There were no complaints about the St George system, but there is no public transportation in Hurricane. Greyhound is non-compliant with “special handling” of bags that, due to ADA accommodation, are supposed to stay with travelers at all times. Often bags are separated from owners and may contain medically necessary supplies.

Ideas to improve services

- Increase collaboration between Red Rock ILC and DLC. Get Cedar City involved in Red Rock ILC.

Wayne County – Loa

Population: 2,554
 Residents with disabilities (% and n): 15% – 385

Issues

- *Transportation:* There is no public transportation or van service in Wayne County. One parent of a child with a traumatic brain injury has to drive their child over one hour, one way, to school because he is unable to sit on the bus that long. She would like the school to provide classes for her child over the ed-net computer system. A disabled Veteran leans on friends to drive him where he needs to go. There are two medical alternatives: the Senior Citizens van will transport people to Richfield for appointments and the Utah Central Mental Health will transport people in their van. If people could have transportation available, they also wished they had somewhere to go in their county such as a day center.
- *Medical:* People with disabilities have to travel to Provo or St George to their specialists. Most people are cared for at home. “The Senior’s residence was closed down — now all our elderly have to go Richfield to the care center and we have to drive over an hour to see them.”
- *DSPD:* A DSPD worker from Richfield stated there are no DSPD providers in Wayne County. People in these communities use the SAM model (Self Administrated Model, usually administrated by a parent or guardian). The town of Hanksville only has one provider. There is too much paper work for respite care and people don’t want to use it — perhaps as a result, there is no respite care available.
- *Mental Health:* Utah Central Mental Health Services exists, but the service provider reported that people want to be counseled over the phone to avoid coming to the office and risk being seen by the community and then labeled.
- *Education:* One mother stated that teachers need more training! One parent wanted accountability for the amount of money their child brings to the school and how that money is specifically spent on their child. One parent asked how she can request an aid for her child, as she was told by the district “there was not enough money.” People drive to Cedar City to see a speech therapist. “I had to learn my rights and stand up for my daughters rights. I went to Philadelphia and got an evaluation saying my daughter needed a speech therapist, but when I told the school that, there was a lot of retaliation.” This parent feels teachers do not want to teach other than the way they were taught, and that they need to be aware of the needs of a child moving into their class room and should be able to request an aide in plenty of time for the next

“You get labeled when you are a person with disabilities and also when you try to advocate you are labeled a trouble maker.”

year. Parents feel they have to educate the teacher about disabilities and educational services available.

- *Employment:* There is no employment for any person, especially people with disabilities. Even child care facilities are seeing a drop in enrollment due to decreases in family size.
- *Housing:* “We don’t have any housing for people with disabilities.” Residents felt a building that used to be a senior home could open for housing or day treatment but “there is no money.” “If we could get a grant we have a lot of CNAs here and a speech pathologist now. We keep our loved ones with us so they don’t have to go away to another part of the state.”
- *Physical Access to Buildings:* This was reported as good; even all the schools are accessible.
- *Community Attitude:* One mother says there is a severe stigma attached to people with disabilities in the community. They are hidden in the community and do not socialize. When they do, they are stared at and made fun of. People are generally closed minded. People with disabilities are afraid that people will treat them differently, and they will not seek out services because they do not want to be identified and noticed. “Most families closet their people with disabilities which is a form of prejudice.” One mother says she rarely takes her child out into the community. People offer a lot of cures to help a child whose brain works differently. “We do have ADHD camps but parents are in denial. We don’t want to open the closet door skeletons fall out. Of all the places I have lived this is the worst place for this type of treatment. They ask what’s wrong with her. The kids laugh and point. They need to be taught.” One participant said “We have generational abusers of alcohol and cigarettes and that’s acceptable, but it’s not ok to have a disability.”

Ideas to improve services

- Educate the community, schools, and medical care providers about the rights and needs of people with disabilities, specifically tolerance training. “Teach the community how to embrace our people with disabilities.”
- Get Celebrate Abilities going again.

Weber County – Ogden

Population: 244,840
Residents with disabilities (% and n): 11% - 26,939

Issues

- *Housing:* Landlord tenant issues are a concern with one participant.
- *Transportation:* Handi-trans was seen by all as a terrible option. One participant tried to work with them, but they were not at all flexible with her. Her job was flexible, so they would call her when they had work, and she often did not get enough notice from her job to reserve a Handi-trans ride.
- *Employment:* One participant was upset about the loss of benefits (including healthcare) they would face if they returned to work, became ill, and lost their SSDI.

“I can’t keep a job because there is no transportation.”

Another participant was frustrated because she was not getting her husband's SSI. Another complaint had to do with the fact that one cannot get disability along with other federal pensions like Veterans. "If two people marry they will lose benefits so many people with disabilities live in sin. This is discrimination."

- *Health Care:* One woman commented that she loved being able to go to the chiropractor with her Medicare, but she wished she could go more often than 12 times a year. This service is better and in the end cheaper than medications.

Ideas to improve services

- Create an advocacy group to work on federal level issues.

Quantitative findings

The following summarizes the data from the project. One hundred and eighty six (n=186) individuals attended the meetings. Of these 51% (n=94) completed the evaluation and 40% (n=74) completed an information request.

These evaluation data indicate that the DLC must provide more opportunities to educate the community about our and other provider's services. The high level of support (90%) for additional, similar meetings in the future is a good sign that this effort was appreciated — but only a beginning to this work. (See Appendix 1 for a detailed evaluation)

Narratives from the L&L meetings were analyzed to provide a more qualitative overview of common findings.

Rights Education		
<i>Topic / Issue / Idea</i>	<i>Rank</i>	<i>%</i>
Overview of rights for people with disabilities	1	42%
Special Education training for parents	1	42%
Train school professionals	2	26%
Train other professionals	2	26%
Advocacy		
Accessibility	1	58%
Special Education – Attend IEPs	2	47%
Transition	3	32%
Barrier		
Rural disability services	1	58%
Employment	1	58%

Transportation	2	47%
Stigma	3	32%
Way to improve DLC services to rural areas		
Follow up meeting	1	53%
Network	2	47%
Outreach	3	42%
Create local Advisory Committee	4	37%

Polling Place Accessibility and Voter Registration

As part of the DLC's work on the Help America Vote Act (HAVA), staff also conducted, when possible, polling place accessibility surveys. L & L attendees were also given information about their right to vote, how to register, and changes in the voting process made through the HAVA legislation. Voter registration forms were available at all meetings.

We surveyed more polling places than expected thanks to the efforts of Carolyn Pence, Alison Draper, Sonia Sweeney, Matt Knotts, Chris Wong, Janis Tetro, Carol Murphy, Virginia Sudbury, Dan Morse, Rob Denton, Khando Chazotsang, Kerry Chlarson, and Harold Fricke, a member of the PAIMI Council.

Polling Place Accessibility

On Election Day the 91 staff and volunteers surveyed 398 of Utah's 1,573 polling places for accessibility. This information was entered into an excel database and is being analyzed by the University of Utah. To date approximately 150 people have been educated by the DLC about the important of accessibility at the polling place.

Next steps

Counties were also asked to assess their accessibility. The HAVA team will compare the information from our findings to that of the counties. At that time we will write a letter to each county clerk and the state elections office outlining the most egregious problems in general and specific terms.

Summary of Listen and Learn Tour

These meetings provided much useful information about the issues relating to people with disabilities in rural Utah and provided the DLC with many relationships with individuals and organizations which we hope to foster. While some of our learning is not new, it has been reinforced in the most direct way possible – from people with disabilities in small communities across this state.

The stories we heard illustrate the detrimental effects of years of state budget cuts, a lack of training and education, and our state's continuing to place the needs of people behind other priorities.

This project also taught the DLC some important lessons about implementing statewide outreach and education that may be helpful to others in the field:

- A minimum of one month advance notice must be given to ensure participation.
- Skepticism and excitement about the possibility of greater collaboration go hand in hand. People in these rural areas are rightly waiting to see what we do with the information and input we have collected to help make their lives better.

The real challenge before the Board and staff of the DLC – and all concerned about the lives of these citizens – is to demonstrate our commitment with action.

Annual Surveys and Focus Groups

Results of the DLC's FY 04 and 05 client and provider survey and Focus Groups

Our annual survey has been a valuable tool in understanding the needs of people with disabilities. In it we ask for opinions on a variety of topics, including satisfaction, training topics, and communication methods to past clients and service providers. The tool has been similar across years and was designed to meet the requirements of our federal partners and give us some insight into how we can improve our services.

Focus groups are another tool we use to learn more from specific populations. We have used this in the past as we have developed new programs and publications or wanted to improve our services to populations with a specific disability or from specific ethnic groups.

FY 05 survey on needs and barriers

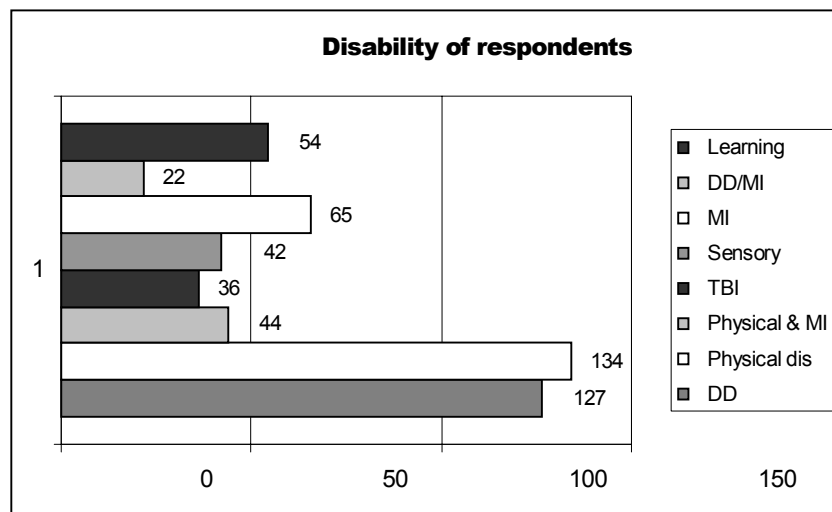
The extensive needs assessment process the DLC conducted in 2005 focused on the needs and barriers people with disabilities face every day. (Please see full report for detail). The survey conducted in April and May of 2005 had our highest return ever — over 500 responses online and by mail.

The survey was sent to a variety of groups. Respondents included individuals on our mailing list, the majority of whom are former clients or people who have attended a training, organizations on our mailing list, recent STAT clients, recent one-on-one clients ('cases'), and a wide ranging group who responded on the web. Being able to break the responses into these groups helps us to be able to more accurately know the needs and concerns of the people we serve and work with to improve the lives of people with disabilities. What we learn for the survey this year is especially important as we plan our goals for the next three years.

Demographics of respondents

Respondents were nicely arrayed across disabilities, with all major disabilities represented.

2005 Needs Assessment



Living arrangements were far less well represented: The last majority of respondents were living independently (77%) or in prison and jail (19%). Far fewer were living in the Utah State Hospital, Developmental Center, or Long Term Care facilities (3%).

Ethnicity was also reflective of the DLC's client base and within state demographic data. More respondents were not white than the general population. It should be noted, however, that the on line survey did not collect race and ethnicity data due to a limit in the number of free questions.

Utah census	Survey	Clients YTD 05	Race / Ethnicity
1%	2%	2%	African American
85%	81%	89%	Caucasian
10%	4%	7%	Hispanic/ Latino
-	6%	<1%	more than one / other
1.7%	3%	1%	Asian/ Pacific Islander
1.3%	4%	1%	Native American

In sum, we can assert that this survey data is broadly reflective of persons with disabilities in the state of Utah who reside in independent housing including family homes. It is not reflective of persons who reside in institutional settings, other than correctional facilities.

Current needs and issues

To help the DLC understand the problems that people with disabilities face in Utah, respondents were asked to identify things that they or family members had experienced in the past 12 months.

These data indicate that:

- Two thirds of people with disabilities have a hard time making ends meet.
- More than half remain unaware of services that might benefit them.
- 40% found dental care illusive in the past 12 months
- 35% thing services are poorly coordinated

More than a third faced these problems:

- Could not find affordable housing
- Could not get mental health services
- Felt they were discriminated against in the workplace because of their disability.

Recent experiences and needs reported by more than 25%	
60%	Hard time making ends meet
54%	Lack of awareness of services available for people with disabilities
42%	Red tape from agencies that serve people with disabilities
38%	Problems getting dental care
35%	Lack of coordination among agencies or service providers
35%	Problems finding affordable housing
32%	Problems getting mental health care
30%	Discrimination getting or keeping a job because of disability
28%	Problems getting health insurance or Medicaid
28%	Problems finding a lawyer who would take my case
28%	Problems getting medical care
25%	Problems getting special education services
25%	Lack of transportation

Priorities for DLC work

Respondents were asked to select ten among a series of possible areas as priorities for the DLC; the following areas were selected:

- Work in the legislature is a clear preference by a large majority.
- Abuse and neglect, one of our core issues, is also seen as a core function of the agency.
- Assistance getting or retain benefits (SSI, food stamps, Medicaid and the new prescription drug program), areas where the DLC has not been active, is a priority for many potential clients. This may be an area ripe for collaboration with groups such as AARP (drug benefit) and Legal Services (SSI and Medicaid).
- Assistance with special education issues remains a high priority.
- Fighting discrimination in the workplace is also a high priority. The DLC has experimented with several models – none very successful – to address this need. The Access and Rights Team is examining a model from Arizona which may help us address this need without consuming the majority of the DLC’s resources.

Top ten priorities for DLC advocacy	
75%	Advocate at the legislature for more state funds for disability services
65%	Help people get or keep SSI / SSDI
64%	Advocate at the legislature about laws that impact people with disabilities
64%	Stop abuse and neglect of people with disabilities
61%	Help people get or keep health care benefits like Medicaid
49%	Make sure children are appropriately evaluated for special education
45%	Help people who have been discriminated in the workplace
44%	Advocate so people can get mental health services in the community instead of the USH
41%	Make sure students get appropriate transition services from school to work
41%	Help people get or keep financial supports like food stamps

Spanish language focus group

As a part of the 2005 Needs Assessment a Hispanic/Latino Focus Group was held in February, 2005 with Spanish speaking individuals with disabilities. Of the eight participants, seven were individuals with disabilities representing themselves, a parent or a friend. The disabilities represented were developmental (autism and Down Syndrome), learning disabilities (ADD/HD), visually impairment and physical disabilities. There were two Spanish-speaking and six bi-lingual English / Spanish speakers. The following summarizes the main issues identified and recommendations for future activities.

Data collection and staff training (race, ethnicity & language):

Like many organizations, the DLC is trying to assess the impact of its outreach on the populations it serves. We asked participants if would be willing to share their race and ethnicity when calling DLC.

- The participants indicated that it would depend on how the questions were put to them and when. They pointed out that during a crisis it would be difficult for them to answer questions about race and ethnicity

- All felt that it was important to inform the caller why DLC wants the information (for example, demographic data collection)
- All indicated that it is very important to train the staff members who take the calls to be respectful and understanding of other cultures

Training topics

The following recommendations were made for discussion and training topics:

- Cultural competence and sensitivity of providers
- Overview of ADA rights, IEP and employment rights
- The rights of undocumented people with disabilities
- The rights of undocumented people whose immigration papers are being adjusted

Recommendations for effective outreach

The group expressed frustration with not knowing where to ask for disability information and support for themselves and their family members. The group made the following recommendations on how to reach people with disabilities in the Hispanic/Latino community:

- *In the hospitals:* People should be given information following the birth of a child with a disability, or after they themselves are diagnosed with disability. “The same way people get information on the disability at the hospital, it will be nice to get information of my rights or child’s rights and where to call if I need help” (translated).
- *In the schools:* When the children are diagnosed with a cognitive or intellectual disability, the schools or the teachers should distribute pamphlets. “Getting the information of where to get help can make a difference, especially in a middle of a crisis” (translated).
- Main sources of information used by this population includes: Spanish media outlets, Centro de la Familia, churches, Children’s Justice Center, health clinics, hospitals, school districts, libraries and Hispanic grocery stores.

Immigration Issues:

The participants were concerned that many services are available only to those individuals who have legal status in the United States.

- There is pressing need for an immigration resource or legal resource for families with mixed immigration status.
- All participants agreed that one of the biggest barriers they face as immigrants to this country is the adjustment of status.
- The immigration status requirement to access many of the services was one of the major barriers.
- U.S. born children face discrimination when receiving services based on the immigration status of the parents, primary language of the parents, or their ethnicity.

Other Recommendations

- The group agreed on the importance of having polite and respectful individual on the line when they call. “Give me some confidence that I will be treated with equality and respect” (translated).
- Treating people with respect when explaining their rights is also crucial. “When the school wanted to put my child in a restrictive facility, my experience with DLC was a good one, they were able to explain to me the law and even though it wasn’t what I wanted to hear I felt respected and I was very appreciative of their information. I knew what battle I was about to fight because I received the appropriate information.” (translated).
- The participants would like a pamphlet in Spanish outlining the rights of people with disabilities. The pamphlet should explain in a simple and concise summary the basic rights, type of services, and resources available.
- Participants requested that DLC identify resources such as attorneys or organizations that have a broad knowledge of immigration laws.
- Participants hoped that there would be an attorney and/or organization that would carry out research to study the impact the laws have on delivery of services to individuals under different immigration status.
- Participants would like more training on how to deal with the IEPs. “It is important to let the community know that they have a right to question the schools and the steps the schools take with the education of their children. Many in our community feel that the schools are doing us a favor in educating our children because of their disabilities, so many parents think they are not in a position to question the decisions made by the school regarding their children” (translated). One option is additional support from the Utah Parent’s Center, such as a support network of parents who can share success stories of how they were able to work through the education system. The DLC and the Utah Parent Center should initiate such an activity.

Summary:

All participants commended the DLC for its commitment to reach their community and for organizing the focus group meeting. They pointed out that as long as an agency made them feel welcomed and respected as individuals, they will continue to work with that agency.

TBI focus group

As a part of the 2005 Needs Assessment a focus group of person with TBI was held by Matt Knotts at Cottonwood Hospital. The wide range of people that attended and shared their experiences of becoming someone with a disability was especially impressive. This was a real eye opener for the facilitator, as most of the people the DLC serves usually have a long history of having a disability, and see the world through that lens. Folks with TBI however, have a unique experience not only have they become disabled later in life, the nature of their disability makes it very difficult to interact with family, friends, and loved ones. As someone said, “we look normal.”

Voices of people with TBI

Mary (not her real name) was honoring her 2 year anniversary of her accident. She remembers waking-up in the hospital completely unaware of what had happened to her. She was the victim of domestic violence. Her boyfriend and hit her with a beer bottle and knocked her unconscious. When she regained consciousness in the hospital, she had lost function to the right side of her body, similar to someone that had suffered from a stroke. Through extensive rehab she is able to walk with a slight limp, but is not able to perform the duties of her job before the accident. She worked in a finance firm, where she helped people qualify for loans and mortgages. At first, her employer welcomed her back, but over time became frustrated and eventually terminated her because she didn't have the stamina to work long hours, and often forgot her duties. She is currently seeking job retraining opportunities, but often becomes overwhelmed and feels that she really needs someone that she can turn to for help.

Bill (again not his real name) recounted his long struggle to figure out what was wrong with him. Bill went in for some routine surgery, but during the surgery something went wrong with the anesthesia, and as a result, Bill suffered a brain injury. This was not initially apparent to Bill or his family. Bill went back to work after the surgery and tried to get along with the things that he enjoyed in his life, going to church, and spending time with his family. He complained of severe headaches, dizziness, and memory loss. He eventually went in for a series of medical tests, which concluded that he had significant brain damage. He tried repeatedly to explain to his boss that he had a brain injury, but to no avail. He tried a new profession, but came up against the same problems. Bill biggest frustration was that he wanted to work and contribute, but could not find an employer that would give him appropriate accommodations.

Jane (not her real name either) was in a car accident, and reported that she was trying to go back to work after one year in rehab. She had applied for voc rehab and had been found eligible. During her medical rehab she was told that in order to go back to work and be successful, she would need a job coach to remind her of duties and to help her stay on task. Jane had just completed the new client orientation with voc rehab, and a number of folks at the support group gave her a wealth of information about how to navigate that system. As one person noted, "If they don't give you what you need, call CAP." Like all of the TBI support group members, Jane wants to go back to work, but is nervous and scared that people will see her as "faking it" and not really having a disability because she's not in a wheelchair.

Summary of main issues:

- Getting and keeping a job
- Complete frustration with Social Security
- Accessing healthcare

FY 04 survey on publications, training and rural services

Focus on publications and training

In response to the Board's Strategic Plan, the 2004 survey focused on two areas in addition to client satisfaction: the DLC's publications and training activities.

Demographics

The following are some interesting facts about the people who responded to the survey:

- 69% use the internet
- 29% have visited the DLC website
- 40% receive Medicaid

Most desired topics for education and training session

One series of questions asked about possible topics for educational training sessions around Utah. Respondents were most interested in services for people with disabilities and the ADA, closely followed by Social Security and self advocacy.

Educational training sessions of interest	
RANK	Topic
1	Access rights under the American with Disabilities Act
2	Services for people with disabilities
3	Social Security
4	Self advocacy and rights training
5	Employment
6	Housing
7	Transportation
8	Special education
9	Abuse and neglect
10	Voting

How to best provide services statewide

We also asked for opinions on various ideas about how the DLC can best provide services to the entire state, many of which may be applicable to other agencies. The most strongly supported ideas were

- having a special hotline just for clients
- holding legal training in various areas
- dedicating a staff person to do outreach and help people in rural areas

Ideas for how to better serve the entire state.	
RANK	Method of providing statewide services
1	Dedicate a staff person to do outreach and help people in rural areas
2	Have staff people around the state
3	Hold legal training in my area
4	Have a special hotline just for clients
5	Hold meetings to learn about needs in my area
6	Post regular updates to the web site
7	Hold drop in days at other disability groups / providers

Appendix 1 – Evaluation Data from L&L participants

Evaluation Data

The following is cumulative data received via surveys from participants in the L & L tour:

Evaluation data	% yes
The representative presented the information clearly	95%
The presentation was an appropriate length of time	67%
The presentation was NOT detailed enough	19%
I have a better understanding of the work of the DLC	77%
I would contact the DLC in the future	89%
I would refer clients to the DLC	90%
I would like a community dialogue organized again next year	88%
Information requests	% yes
Receive advocacy alerts	74%
Attend training in my community	69%
Attend a public meeting about disability issues in my community	63%
Be a member of a local DLC advisory council	47%
Be considered for membership on the Board of Trustees	20%
Receive DLC newsletters	83%
Receive DLC surveys	63%
Other	27%

The Disability Law Center

The Disability Law Center is a private non-profit organization designated by the Governor to protect the rights of people with disabilities in Utah. Our mission is to enforce and strengthen laws that protect the opportunities, choices and legal rights of people with disabilities in Utah. We envision a just society where all people are treated with equity, dignity, and respect. Services are provided to accommodate individual needs and are free of charge to all eligible individuals in Utah.

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Disability Law Center

at the Community Legal Center
205 North 400 West
Salt Lake City, Utah 84103

801-363-1347
800-662-9080 (voice)
800-550-4182 (TTY)

To get help from the Disability Law Center, call 1-800-662-9080 (voice) or 1-800-550-4182 (TTY) to speak confidentially with one of our Short Term Assistance Advocates. They will provide you with the information and/or assistance you need. Office hours are Monday through Friday 8:30 a.m. – 5:00 p.m. Or visit our new and improved website: www.disabilitylawcenter.org.