

March 20, 2019 Utah Children's Care Coordination Network Learning Session

“Legal Issues and Services for Families with Children and Youth with Special Health Care Needs”

Here is a summary of the UCCCN March 20th, 2019 Learning Session. You can also access a [recording of the entire meeting](#) should you wish.

Background and Current Disability Rights & Laws – Disability Law Center, Nick Jackson & Amberly Datillo

See the full presentation [slides](#).

The Disability Law Center's mission is to enforce and strengthen laws that protect the opportunities, choices and legal rights of Utahns with disabilities. A private 501c3 non-profit organization, the Protection & Advocacy agency for Utah.

History: People with disabilities were kept in jails, cages, chains. Eugenics, sterilization for 10s of thousands. Dorothea Dix in mid 1800s was an advocate. First schools, first college for the deaf. Tactile languages (NY Point, Braille) for the blind were created. [Gallaudet University](#).

1930-40s – parent groups organized. 5 moms in Cleveland in 1933. Wanted to keep their children at home and were able to get the first special education classroom in the school.

Institutions were established but also became overcrowded and the residents were often maltreated. Fred Kaplin, professor took photos in 1966, called the “Christmas in Purgatory” expose. Also, Geraldo Rivera's story in 1972 on Willowbrook (NY) captured the public's attention and resulted in legislation. Now there is an organization like the DLC in every state – Protection & Advocacy (P&A) agencies.

Civil rights movement, plus the return of veterans with disabilities after war. (But still “separate but equal” and not good) FDR's disability becoming known helped, too. 1964 Civil Rights Act – only covered employment for race, color, sex, religion, national origin. People with disabilities weren't protected and housing wasn't part of the Act. 1968 – Fair Housing Act was finally passed; one of the main laws that the DLC uses to enforce rights.

“Nothing about us without us.” Berkeley was one of the hot beds of activity; Ed Roberts. “Rolling Quads” – sit ins, demonstrations, fighting for equal access. 1970s – activism for the Rehabilitation Act. It was issued in 1973 (President Nixon) after a 25-day occupation of the San Francisco HEW federal building.

Education for those with disabilities – early 1970s saw two critical cases. Established that children with disabilities have a right to a public education. 27 federal court cases followed but ultimately the Education for all Handicapped Children Act was passed in 1975, now called the IDEA. All public (and charter) schools who receive federal funds must give children the same educational opportunities. IEPs

and the least restrictive environment. Education must be meaningful and help a child achieve everything they can. All children with disabilities must be evaluated for services. ADA, Section 504, etc.

Policy that followed:

- Urban Mass Transit Act (1970)
- Developmental Disabilities Bill of Rights (1975)
- IDEA (1975)
- Amendments to the Rehabilitation Act (1983)
- Mental Illness Bill of Rights (1985)
- Others
- Fair Housing Amendments Act (1988)
- Americans with Disabilities Act (ADA) of 1990 – most significant legislation

ADA

- Title I: Employment – reasonable accommodations. EEOC enforces
- Title II: State & Local Government public services. Includes public transportation. Dept of Justice enforced.
- Title III: (slide missing) Public Accommodations and commercial facilities. Goods, services, facilities and accommodations. Inns, hotels, dining, stores, private transportation, places of public displays. Must be accessible – new buildings and retrofits to existing buildings. Service animals allowed.
- Title IV: Telecommunications – covers internet companies, too. Regulated by the FCC.
- Title V: Miscellaneous

1990s – Medicaid Waivers. Parts of the Medicaid law was waived so that people could receive services in the community (at home) rather than only the hospital. Based on the Katie Beckett case and the “Katie Beckett Waiver Program.” Over 1 million people have been able to receive services in the community because of the home-based waiver program.

Supreme Court decision on *Olmstead v L.C.* Affirmative obligation for states to demonstrate a commitment to deinstitutionalization. Applies to many situations: segregated school systems, forensic hospitals, nursing homes, more.

New - HCBS Settings Rule of 2014 – Home and community-based services are not an entitlement for Utah Medicaid recipients. States were allowed to have waiting lists. The new rule means that Utah must ensure that these service providers in the state allow choices and doesn't segregate people with disabilities.

Legal Resources & Services for Utah Families with CYSHCN

Utah Legal Services (ULS) – Amy Morgan, Managing Attorney, Intake

See [the ULS flier](#) and [their basic PPT presentation](#), <https://www.utahlegalservices.org>

- Eligibility for ULS services: Low income, civil cases (no criminal cases), must have some qualifying legal status in the US. ULS is there to “level the playing field,” give those who wouldn't normally have an attorney a voice.

- Financial eligibility must be met (exceptions for those seeking help with protective orders, stalking injunctions or senior citizens – those 60 and over). Intake required. Online or by phone, M – F between 9 am – 2 pm. They have Spanish interpreters on site, have an interpreter service for other languages.
- Instant messaging available for intakes submitted online, as well
- Once guidelines are met; attorneys and paralegals available immediately.
- 4 main areas:
 - Family Law – majority of their cases fall here. Stalking and protective orders, divorce, custody, guardianship, adoptions – advice. CYSHCN specific: custody and parent-time arrangements for the child’s best needs. At age 18, can help with the guardianship.
 - Public Benefits Task Force – SSI & SSDI – can help with applications, appeals, reviews and overpayments. WFS - Medicaid, child care assistance, food stamps, unemployment benefits, cash assistance.
 - Housing – evictions, lockouts, repair issues. Loss of housing subsidies. Only help tenants (not landlords). Companions, service animals. Habitability issues (mold, etc.)
 - Consumer issues – contract review, enforceability. Debt collections, bankruptcy, identify theft. Collection of medical bills, garnishments.
 - Sub-task forces
 - Senior Task Force (advice only if they don’t meet the financial eligibility; can provide advice on wider range of issues)
 - American Indian
 - Agriculture (can help non-citizen agricultural workers with immigration issues)
- ULS took over 15,000 calls last year. For those they couldn’t help, they refer them to other resources.
- ULS has offices throughout the state. No restriction on location (although Legal Aid Society of Salt Lake is the primary provider of services for family law in Salt Lake County).
- Brochures (attached). Amy is the intake manager.

Disability Law Center Services – Amberly & Nick

<http://www.disabilitylawcenter.org/>, (801) 363-1347 or (800) 662-9080. See [their Services ppt](#)

The DLC is the Protection & Advocacy agency for Utah (one in every state)

- No income requirements (except in the fair housing section) – just have to have a disability (any kind). Services are free of charge.
- P&A agencies:
 - have the authority to provide legal representation and other advocacy services, under ALL federal and state laws, to ALL people with disabilities
 - maintain a presence in facilities that care for people with disabilities
 - ensure full access to inclusive educational programs, financial entitlements, healthcare, employment and housing

DLC has 4 long-range goals:

- People with disabilities will be free from abuse and neglect.
- People with disabilities will receive appropriate services.
- People with disabilities will be free from discrimination.
- People with disabilities will have equal employment opportunities.

DLC Services:

- Investigation & monitoring
- Mediation & negotiation
- Outreach & community education
- Public policy advocacy
- Self-advocacy support & training
- Representation in administrative & court hearings
- Individual & class action litigation

DLC Teams:

- Abuse & Neglect – they do a lot of work in prisons & jails
- Access & Rights - includes the Fair Housing team, which serves anyone protected by the statute
- Education – got corporal punishment banished in Utah schools in 2017
- Employment – Client assistance program, social security (related to work), employment discrimination
- Community Integration – system-based discrimination; advocacy around the settings rule, Medicaid, denials, appeals, illegal discharges
- Short Term Assistance Team - referrals, advocacy

Holy Cross Ministries – Gabriella Archuleta, JD, MPP, Immigration Dept.

www.hcmutah.org [HCM flier](#), [HCM Immigration Relief for Survivors of Violence presentation](#)
(801) 261-3440, ext. 711, garchuleta@hcmutah.org

Holy Cross Ministries have been in Utah for over 100 years with a medical focus. In 1994, the Sisters created Holy Cross Ministries (a 501c3 nonprofit organization) to continue their tradition of compassionate service. Through innovative services and programs, Holy Cross Ministries and its collaborative partners in the community, has been successful in delivering compassionate service and effective programming driven by the commitment to serve those in need.

Programs:

- Health – trauma informed counseling and Promotora outreach program (boots on the ground).
 - HCM offers prenatal classes
 - CYSHCN Spanish Speaking program @ South Main Clinic: Ninos Especiales Familias Fuertes/Strong Families of Children with Special Needs (NEFF) Support Group. Contact: Esperanza Arias (801) 261-3440 x 341, earias@hcmutah.org
- Education – School Readiness, Parents as Teachers, among others
- Justice program – immigration department. Consultations provided free or (more typically) low cost. Many people don't qualify but learn why through the consultation (may then avoid being taken advantage of)
- No specific immigration benefit for having a child with special needs
- Citizenship services – make be exempt from taking the citizenship exam in English. The letter from the health provider needs to make the connection between the ability to do the exam and the health issue.
 - U Visa Relief – to help bring crime to light
 - Please, be very detailed if you suggest domestic violence in the medical report. This may be the reason the individual can get the U Visa (because there isn't a police report)

- Letters – services for clients can be coordinated; depends on what the client is applying for. Want the letter to be tailored. The client may need to show exceptional hardship (like needing to care for their child with special needs; need to show that staying in Utah will allow services that wouldn't be available in their home country)
- See the uscis.gov website – US Citizenship and Immigration Services. Forms list has instructions (look for U Visa, Form I-918).
- Individuals who apply for green cards must complete a medical exam – must be a designated civil surgeon: www.uscis.gov/greencard/medical-exam-find-a-doctor
- DACA: We charge \$100. Appointments every Thursday afternoon. USCIS is accepting renewal applications only.
- Here is a website of all DHS Computer Matching Agreements and Notices: <https://www.dhs.gov/publication/computer-matching-agreements-and-notices>

Family Voices – Gina Money

[Utah Family Voices website](#), [National Family Voices website](#)

Julie Beckett (mother of Katie Beckett) is a co-founder of the [national Family Voices](#). In 1986 there were no technology waivers in Utah. Utah, 33 years later, is still not fully recognizing the Medicaid waivers. MCCW will have some open enrollment in May. Just a little bit of good news out of the last Legislative session.

[Immigration toolkit out of the national Family Voices](#). Handout on the table; all of them are available for download and customization.

- Sounds like the toolkit will help greatly with the documentation mentioned by Gabriella. Go to familyvoices.org – search for 'immigration'
- Templates – Introduction for letters of support, actual letter of support template
 - Details and correct emphasis are very important
- Document checklist – includes education, medical, special documentation, etc.
- Child care options in case the parent/guardian is removed
- Families' rights
- Help identifying the right physician to write the letter of support
- Forms of ID

Questions

From ULS presentation:

- Eligibility? financial requirements are 125% of federal poverty level. Can go up to 200% under certain exceptions.
- Pat Rowe: children age 18 still in high school and decision making. Insurance has to treat them as adults. Same requirements for the Utah Legal Services.
- Guardianship cases, particularly in regard to children about to turn 18. Assuming the individual contacting ULS is qualified for services, they will typically will allow a guardianship case through for services a few months prior to the child's 18th birthday because they understand the need for action to occur prior to that date; however, ULS staff attorneys would only provide advice in these types of cases. They would then be sent to the ULS pro bono department to be reviewed for possible

placement with a free attorney who volunteers through ULS. In addition, for parents who do not meet any of the ULS citizenship / legal residency requirements, but have a child who is a citizen - while ULS could theoretically help them apply for / or appeal a denial of benefits on behalf of their child (such as disability, Medicaid or food stamps), ULS wouldn't be able to help these same parents with a guardianship case because unlike the benefits cases, the guardianship is not the child's issue, it is the parents' issue, so the child's citizenship as a basis for eligibility for ULS services could not be used.

From the DLC presentation:

Question: service/comfort animal for apartment residents. Complicated ... pretty easy to qualify for an emotional assistance animal in the home and landlords can't charge any extra.

From HCM presentation:

- The question-asker's organization helps a lot of families with children who are citizens but parents aren't. Concerns about the parents' immigration process if they get certain services. Valid? Possibly, yes. Can't be a public burden. Must show that the U.S. citizen or lawful green card holder child is the one getting the benefits. Can get tricky. Matters what benefit they are applying for.
- Does the Social Security Information share information with Department of Homeland Security?
Yes.
 - Effective 12/28/2018, Social Security Administration has a policy on how and what information is shared with DHS, found here: <https://secure.ssa.gov/poms.nsf/lnx/0203313095>
 - Effective July 19, 2017 – Jan. 18, 2019, DHS and SSA held a computer matching agreement where DHS informed SSA when immigrants left the United States, found here: <https://www.dhs.gov/sites/default/files/publications/privacy-cma-claims3-ice-social%20security%20administration-november2017.pdf>
 - o Gabriella did not find any indication that the agreement has been renewed.

Panel & Audience Discussion

- Wait times for individuals seeking services from these organizations?
 - HCM – can see people for consultation in 2 – 4 weeks but may take a fair amount longer for the actual case
 - DLC – special education backlog right now, but otherwise similar to HCM
 - ULS – immediate advice once they are found eligible
- Emotional Service Animal letter for landlord – who should write? Anyone *qualified* may write (the physician doesn't have to be the one). Should be from someone who knows the individual and their needs.
- Undocumented parents who are reluctant to participate in any gov't program. Reassurance that they will be safe? HCM - Have to build trust. Focus on confidentiality. ULS – agricultural outreach workers. Promotoras and Spanish speaking families at UFV. None of these orgs will share information with ICE.

- Immigration process in progress or about to be initiated, so parents are very nervous. Can refer them to HCM? Yes, to the legal department about services that they should avoid.
- Can SSI report to ICE? She's had reports that illegal parents have been threatened. HCM – ICE prosecutors do seem to have a lot of info. F/U: Short answer is Yes, see above.
- SSI applications and appeals help? ULS and UFV. ULS can go before an administrative law judge on behalf of the client if needed.
- Do you need to prove disability with documentation for the DLC services? Not usually, the ADA is easy. Getting a statement from a third party: teacher, aid, even a family member.
- Is the designation of disability fluid? Nick: it is fluid, can change. SSI changes when you apply for a child under 18 and then when the application is for a child over 18. It's more about how the disability impacts the individual's daily living. ULS- the changes when the child turns 18 are really important and families need to be aware of them. There are SSI reviews and the individual has to continue to show their disability
- Financial & estate planning? Nick – DLC just got a grant around this and should be able to help more right away (Andrew Riggles – Benefits Planner, can give advice). Will still need an attorney. ABLE accounts don't require an attorney. ULS cannot provide special needs trust services. UFV – has a list of financial planners (there are 3 Benefits Planners with Voc Rehab). Two individuals with disabilities getting married can really affect their benefits.
- Child is citizen and nearing age 18; can ULS help if the parents are not documented? ULS would review it on a case by case basis; would need to be acting very near the birthday. HCM – connect with the consulate for the parents' origin country. Consulate may be able to help cover some fees, may also help get dual citizenship for child if the parents are deported and can ease the child's entry into the non-US country. DLC - Supported decision making movement which may mean formal guardianship is not needed. Trainings should be available regardless of status of parents. UFV – met with DCFS yesterday; DCFS assured Gina that they don't care about legal status of parents. UFV is working with another non-profit and the courts and South Main Clinic to offer specific classes in Spanish for families whose children are nearing age 18. When families seek full guardianship, the young adult's rights are reduced, like voting.
- MCCW open enrollment in May: how many? The eligibility is tightening up; all the applications will be reviewed and be based on details. Amberly: trying to advocate for increased access to community services. Always looking for voices to help at the legislature.
- Custody cases - the physician practices get asked for records. Can the practice ask for general advice on how to navigate the back and forth? DLC – ask General Counsel for the organization in question. If the family member is a client of ULS or DLC, a release would be needed for them to speak to the physician practice. Gina – trying to find info for parents in custody questions. DLC – a group of attorneys who used to work for the DLC who can do handle estate planning. The Utah State Bar has a good referral service.
- **Reminder:** call the Utah Parent Center **first** for school / IEP questions.