



The Arc™

Colorado

2013

Chapter Report

Achieve with us.

Federal Legislation-Policy

The Arc of Colorado actively promoted action by members and colleagues in the disability community to:

- Contact members of Congress to save Medicaid from onerous cuts as part of deficit and debt reductions
- Advocate for the ABLE Act to allow families to provide for the financial future of family members with IDD
- Support state and federal efforts to expand Medicaid coverage through buy-in programs to ensure that all persons have access to health care coverage.
- Support for the Convention on the Rights of Persons with Disabilities

At the annual Public Policy Seminar, Arc members from CO met personally with Senator Bennet and Representatives DeGette, Coffman, Tipton, Gardner and Polis in Washington DC and in home district offices to express the critical need to maintain Medicaid for people with IDD. (note: The Hart Senate Office building was on lock down due to a security concern that prevented meeting with Senator Udall.

The Arc of CO, with more than 700 other local and state chapters, advocated for these issues in 2012-13:

Budget and Tax Policy

Determine the availability of federal social insurance (Social Security, Medicare), safety net (Medicaid, Supplemental Security Income (SSI)), and discretionary programs (such as housing, education, employment, transportation) that people with I/DD rely on for their health, safety, and wellbeing. Sufficient tax revenue must be raised in order to properly fund these programs.

Medicaid

Overwhelmingly the largest funding source of both acute health care and long term services and supports for people with I/DD. The program must be preserved and rebalanced to make home and community based services the norm and institutional services the exception.

Long Term Services & Supports

Critical for people with I/DD who frequently have lifelong needs for assistance with activities of daily living, such as getting dressed, taking medication, and preparing meals. These services must be widely accessible, consumer controlled, and provided in the community without the requirement that people impoverish themselves.

Employment

The cornerstone for community living for most adults with I/DD who are able and willing to engage in meaningful work. Integrated employment programs, including supported employment, must be properly funded and administered to provide job development and placement, skills training, job coaching, and other services necessary to help find and maintain employment.

Federal Issues

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The Arc with UCP (United Cerebral Palsy), AAIDD (American Association on Intellectual and Developmental Disabilities), ANCOR (American Network of Community Options and Resources), AUCD (Association of University Centers on Disabilities) and NACDD (National Association of Councils on Developmental Disabilities) work together to shape, expand and maintain, a strong federal role that provides benefits, services and supports as well as protection of civil rights for people with disabilities.

Each year, The Arc with partner organizations adopts a broad policy agenda outlining priorities for Congressional action.

The Arc of Colorado participates in bi-monthly conference calls on federal legislation with staff of The Arc policy office and shares updates on critical issues with Arc chapters and others interested in disability issues.

Housing

Critical for most people with I/DD to live in the community. There must be an adequate supply of safe, accessible, and affordable supportive housing.

Family Support

Essential for caregivers, especially those who are aging, who provide care in the community. Counseling, support groups, respite, training, cash assistance, and information and referral must be made widely available to family caregivers.

Education

The gateway to achieving full potential and independence for people with I/DD. The education system must have high expectations, offer integrated instruction by highly qualified teachers, require appropriate assessments, and use only positive behavioral supports to address problem behaviors.

Social Security & Supplemental Security Income (SSI)

The primary income sources for many people with significant disabilities to meet their basic needs for food, shelter, and clothing. Benefits and eligibility must be maintained and the long-term financial future of these programs must be considered outside of budget reduction efforts.

Transportation

The pathway to employment, health care, recreation, and other aspects of community living for people with I/DD. Accessible transportation programs must be properly funded and administered and anti-discrimination policies in transportation must be enforced.

Technology

Instrumental in making communication, education, independent living, and employment opportunities available for people with I/DD. Technology must be customized and made widely available to persons who may benefit from it.

Civil Rights

The foundation for the services and protections that people with I/DD enjoy today. Civil rights must be preserved through vigilant enforcement of laws and regulations as well as strong opposition to efforts to limit the rights of people with I/DD.

Health Care

Critical for people with I/DD to improve and maintain health and functioning. Health care systems must be accountable for providing timely access to high quality, comprehensive, accessible, affordable, and appropriate services that meet individual needs.

Direct Support Professionals

Constitute the backbone for community living for people with disabilities. A well-trained, adequately compensated direct support workforce is essential to providing the necessary supports and services to our constituents, where they live and work.

2013 State General Assembly Action

The 2013 session of the Colorado General Assembly convened in January with an ambitious agenda to tackle complicated and often controversial issues including civil unions, gun control, capital punishment, Medicaid expansion, total revision of the school funding formulae, and regulation of recreational marijuana use. The latter two issues required voter approval of new taxes.

These issues dominated the 2013 session. Nonetheless, several measures were passed that support services for people with disabilities.

Funding for services for people with IDD was significantly increased. The 2013 budget was signed into law by Governor Hickenlooper on April 29.

SB 230 (Long Bill) provides:

- \$13.5 million additional dollars for FY 14 to fund 765 new resources for HCBS Medicaid waivers for Children's Extensive Support, DD Waiver, and Supported Living Services. These resources will also cover the cost of children in foster care aging out of the Children's Habilitative Residential Program (CHRP) and emergency placements. This is the most significant increase in IDD services in many years.
- \$5.4 million to transition 47 adults with IDD currently in nursing facilities to community based settings and to transition 19 individuals currently at Regional Centers.
- \$2.9 million increase for the Early Intervention program to account for anticipated increases in enrollment of children birth to age three.
- \$2.987 million for expected increases in costs of eligibility determination resulting from changes to DD Definition rules.
- \$50,000 for initial work to conduct a gap analysis to explore barriers to mental health services for people with IDD. (See page 5)
- **Community provider rate:** The bill includes an increase of \$78.3 million total funds, including \$36.2 million General Fund, for the following community provider rate increases:

FY 2012-13

- ◊ 4.5 percent for home health, private duty nursing, and home and community based services

FY 2013-14

- ◊ 3.6 percent for home health, private duty nursing, home and community based services
- ◊ 4.5 percent for dental services
- ◊ The greater of current rates or 105 percent of Medicare rates for family planning services
- ◊ 2.0 percent across-the-board for all other providers decreased in prior years.

State legislation

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The Arc of Colorado, with input from all CO chapters of The Arc adopted a general public policy platform for 2013. The Board of Directors approved the policy agenda in January of 2013.

The Arc of CO supported legislation and policies to:

- *Provide adequate funding to preserve and strengthen the CO Medicaid system and other state programs for persons with disabilities.*
- *Ensure that CO students with disabilities have access to free, inclusive, and supported education.*
- *Simplify publicly funded systems and remove unnecessary and outdated regulatory barriers.*
- *Promote and protect the civil rights of persons with disabilities.*

Other Long Bill actions - Department of Human Services

Division of Child Welfare

- Adds \$6.1 million General Fund for in-home family supports and prevention services provided through the Family and Children's Programs line item.
- Adds \$2.2 million General Fund and 1.0 FTE to fund prevention services for families at risk of entering the child welfare system by expanding the SafeCare program to nine sites throughout the State.
- Adds \$1.5 million General Fund and 0.9 FTE to augment the existing Nurse Family Partnership program and build a partnership with child welfare agencies and other child abuse prevention programs.
- Adds \$1.1 million General Fund and 0.9 FTE for implementation of a community-based child abuse prevention services program in six initial sites.

Mental Health

- Adds \$17 million General Fund for mental health mobile crisis response
- Adds \$4.3 million General Fund for community mental health centers to provide additional assertive community treatment, intensive case management, housing vouchers, and residential options for individuals requiring protective oversight and personal services.
- Adds \$3.0 million General Fund offset by a decrease of \$3.0 million federal TANF block grant dollars for the Family and Children's Programs (core services) line item.
- Adds \$2.1 million General Fund and 0.9 FTE to contract for the creation of a 20 bed, jail-based restoration to competency to stand trial program.
- Adds \$1.1 million General Fund to increase community behavioral health resources in schools.

Specific Legislation

HB 1314 (JBC Bill) transitions the administration for people with developmental disabilities services from the Department of Human Services to the CO Department of Health Care Policy and Financing. The transition creates a division for developmental disabilities in the Office of Community Living at HCPF. The effective date is March, 2014. Reports to the JBC from staff and from representatives of CCBs, service providers and a statewide advocacy organization are required.

SB 200 (Sen. Aguilar) expands Medicaid eligibility by allowing money in the provider fee cash fund to be used to increase the income eligibility for parents and caretaker relatives of children from 61% to 133% of the Federal Poverty Level and increase the income eligibility for childless adults or adults with dependent children up to 133% of FPL. Additionally, to implement the Affordable Care Act, the bill amends the optional eligibility groups in CO's Medicaid program to increase the income eligibility levels for parents and caretaker relatives of children from 100 to 133% of FPL and for childless adults.

SB 167 (Sen. Steadman) changes the title of Intermediate Care Facilities for the Mentally Retarded to Intermediate Care Facilities for Individuals with Intellectual Disabilities. The bill also transfers the responsibility for administration of the provider fee from DHS to HCPF.

HB 13-1081 (Rep. Duran) creates a grant application program for schools districts, BOCES, and charter schools to access funds for developing comprehensive human sexuality education programs that are evidence-based, culturally sensitive, medically accurate, age-appropriate, reflecting positive youth development approaches, and that comply with statutory content standards. The bill also requires that schools that receive such funding will be required to implement an "opt out" policy rather than "opt in" policies.

HB 1136 (Rep. Levy) creates the Job Protection and Civil Rights Enforcement Act. This bill allows compensatory and punitive damages in employment discrimination cases brought under state law against employers where intentional discrimination is proven. Currently only employers who employ 15 or more people are subject to these requirements.

HJR 1023 (Rep. Young) expresses legislative intent that person centered principles and self-determination options be included as primary drivers of efforts to re-design Colorado's long term service and support system.

State Public Policy Activity

DD Definition Rule Revisions

In July, 2013, the State Board of Human Services approved changes to Colorado rules regarding definition of developmental disability and eligibility for services for people with IDD. The rule change process was launched nearly five years ago. Colorado statute is clear that a developmental disability can be determined by intellectual/cognitive criteria OR adaptive behavior criteria. State rules are now consistent with state law. The Arc of Colorado has been active in the process since it began.

Community First Choice

The Affordable Care Act includes a provision that rewards states to strengthen state Medicaid plans by including services that foster community inclusion and independence. States that opt to add personal care and other services to support community living to the state plan for all people who meet an institutional level of care could receive an additional 6% across the board increase in federal Medicaid (state plan) funding.

The Executive Director of The Arc of Colorado serves on the CFC Council. The group is charged with making a recommendation to the Community Living Advisory Group, HCPF (and to the General Assembly) about the CFC option in January of 2014. The fiscal impact of including these benefits for all those who would be eligible is underway.

Community Living Advisory Group

Governor Hickenlooper appointed the CLAG in January of 2013. The Executive Director of The Arc of CO and The Arc of Arapahoe and Douglas Counties serve on the committee. The CLAG is charged with developing broad recommendations to the Governor and General Assembly to increase access to community supports for long term services to enable people to live where they choose with the supports they need to participate in community life. The CLAG final report is due in October, 2014.

Directors of chapters of The Arc in CO serve on all six subcommittees of the CLAG which are charged with proposing recommendations related to:

- Waiver simplification (The Executive Director of The Arc of CO co-chairs this committee)
- Care coordination
- Single entry point re-design
- Regulatory reform
- Workforce development
- Quality assurance

HCBS Waiver for Persons with Developmental Disabilities Re-Design

The first major recommendation from the Community Living Advisory Group centers on exploration of a new adult waiver for adults with IDD that would create a single waiver in lieu of the two waivers currently in place. The waiver re-design workgroup was appointed in October, 2013. The Executive Directors of The Arc of Colorado and The Arc of Arapahoe and Douglas are included.

Colorado Cross Systems Crisis Intervention and Prevention

Inadequate access to mental health services for people with IDD has been a long standing problem in CO and elsewhere. In 2013 with support from an appropriation sponsored by the JBC, the Colorado Collaborative for Autism and Neurodevelopmental Disabilities Options (CANDO) launched a “gap analysis” to identify funding, policy, and other barriers that limit access to mental health and Behavioral services for people with IDD. The Executive and Associate Director of The Arc of CO helped to facilitate 11 community meetings throughout the state to gather input from providers, families and other community agencies.

Recommendations to the General Assembly will be forthcoming in January of 2014.

Policy Representation - The Arc of Colorado

The Arc of Colorado Executive Director serves on the following policy committees and work groups:

- Community Living Advisory Group
- Waiver Simplification Committee - Co-chair
- Community First Choice Council Steering Committee -Expansion of Medicaid to Adults with Disabilities
- Medicaid Infrastructure Grant
- Colorado Choice Transition Advisory Council
- Dual Eligibles Developmental Disabilities Task Force
- JFK Advisory Council
- Gap Analysis Steering Committee
- Colorado Collaborative for Autism and Neurodevelopmental Disabilities Options -co chair of mental health committee
- Colorado Health Care Innovation Plan Advisory Group
- Colorado Department of Housing -Disability Advisory Panel
- RMHS—Mill Levy Advisory Committee
- CO Non Profit Association - Public Policy Committee

The Associate Director of The Arc of Colorado currently serves on:

- Care Coordination Subcommittee of the Community Living Advisory Group
- Children’s Disability Advisory Group
- Colorado Fetal Alcohol Syndrome Commission
- Colorado Special Education Advisory Committee
- Colorado Respite Coalition
- Gap Analysis Committee

National policy related activity

The Executive Director of The Arc of CO with colleagues from The Arc of Indiana and The Arc of Tennessee represented The Arc at the National Council of State Legislators annual meeting in Atlanta, GA in August, 2013.

The Arc of CO Executive Director with representatives from five other state chapters participated in a meeting in Washington DC in Sept., 2013 with Peter Berns, CEO of The Arc and Thorkil Sonne, CEO of *Specialisterne*, a company that brokers jobs in the technology world for people with autism to explore a formal partnership between the two organizations.

Critical Issues

In January and March of 2013, The Arc of Colorado Board of Directors met to identify critical issues for the coming two to three years. With input from local chapter executives, a facilitated discussion led to identification of the following issues. Budget and program planning will be consistent with the critical factors:

1. Public Policy Advocacy

must remain as the top “critical” responsibility for the state chapter

Issues

- Federal level legislation
 - ◊ Social security
 - ◊ Medicaid changes
 - ◊ Allocation of resources
- State level legislation
 - ◊ Conflicts of interest in CO system
 - ◊ Wait list
 - ◊ Criminal justice system—for persons with IDD who are victimized as well as for those who are accused
 - ◊ Resource allocation
 - ◊ Respite
 - ◊ Funding
 - ◊ Access to mental health services
- State system level policies/practices
 - ◊ Waiver re-design—including consolidation of all children’s waivers and new adult waiver with flexible services and supports
 - ◊ DD definition rule implementation
 - ◊ Community based services—need to expand and make more flexible so that transition from school to adult life can be less complicated and to allow many people to get what they need through the Medicaid state plan.
 - ◊ De-regulation

Implementation

- Continue support for contract lobbyist—expand scope if needed
- Ensure that public policy advocacy remains the top chapter priority regardless of future staff changes
- Continue to support state chapter involvement with The Arc US at federal levels
- Target rural areas for strategic “community organizing” and legislative advocacy education

2. Public awareness and audience specific education

Issues

- Public Awareness
 - ◊ Continue/expand special events/projects—e.g. DD film festival; Families in Action
 - ◊ Support local chapters in community based public awareness activities
 - ◊ Build awareness of The Arc—who we are, what our chapters do, how we can help, etc.

- Audience Specific Education
 - ◊ Families in areas not served by a local chapter
 - ◊ Self-advocates in areas not served by local chapters
 - ◊ Community opinion leaders
 - ◊ Legislators
 - ◊ Allied “communities”—e.g. advocates for and providers of services for the aging; TBI; physical disabilities—to help them understand the commonalities and differences re: people with IDD
- Topics
 - ◊ Families: Financial planning, legislative process and advocacy, system design and access, rights and responsibilities, resources, how to “get connected” despite not living in an urban area, Arc chapter establishment and ongoing support
 - ◊ Self-advocates: self-advocacy; public policy involvement; rights protection
 - ◊ Opinion leaders: the basics about IDD and the importance of community integration - build the “business case” for employing people with IDD in rural areas
 - ◊ Legislators: the basics about IDD and development of targeted messages for individual legislators and equally targeted communication networks for key lawmakers

Implementation: The Arc of CO has a much higher and more positive profile at the current time than in many years - but capitalizing on that profile and expanding influence and effectiveness requires additional resources and staffing.

3. Outreach to non-represented areas

Individual advocacy in areas not served by chapters is an important responsibility of the state organization

Issues

- Many problems can be resolved via telephone conversations and e-mail communication but it is difficult to build relationships through these means and reach others in communities with similar problems
- Contract advocacy helps to solve individual problems but does not contribute to expanding The Arc presence and influence
- It is difficult to address systemic community issues that are often evidenced by individual advocacy request through contract services

Implementation: Hire additional staff to support Executive and Associate Director to meet advocacy requests.

4. Governance

Issues

- Board development
- Board structure
- Policies - practices: bylaw revisions; participation of at-large members of the Board; prohibition/traditions re: service provision, etc.

5. Financial Resource Development

Issues

- Policies/practices (service provision - [definition of service]; fundraising; reserve allocation; etc.)
- Board role
- Grants - pros and cons
- Other opportunities - corporate contributions, approaching state government for contracts that fit within mission

Community Participation

In 2013, The Arc of Colorado has participated in, exhibited at, or provided sponsorship for:

- National Down Syndrome Congress
- Alliance Summit
- Achievement Challenge - Colfax Marathon
- Autism Awareness Day at the Capitol
- The Arc of Pueblo's Golden Tortilla
- 2013 Step Up for Autism Walk
- Colorado Special Education Advisory Committee Resource Fair
- The 5th Annual Jewish Disabilities Awareness Day - *Finding Ability in Disability*
- The National Association for the Dually Diagnosed (NADD) Conference
- Colorado Cross Disability Coalition Awards Luncheon
- Parent 2 Parent Mothers Day Tea
- Rocky Mountain Human Services Wounded Warrior Recognition
- The Arc of Aurora - Flame Concert
- Specialisterne Colorado
- 2013 Coleman Institute Conference
- Autism Resource Fair
- Junior League Public Policy Committee
- CO Culture Change Accord Conference
- CO Non-Profit Association Fall Conference & Exhibition
- Kids Choice Health and Wellness Fair

Developmental Disability Awareness Month

In March 2013 The Arc of Colorado and all eleven Colorado local chapters of The Arc celebrated National Developmental Disability Awareness Month with the second annual community wide awareness event *Achieve With Us Colorado* Film Festival showcasing films related to the field of developmental disabilities. This event gives the community a glimpse into the lives of people with intellectual and/or developmental disabilities.

Highlights from March 2013

- Hosted four *Achieve With Us Colorado* Film Festivals: Denver, Northern Colorado, Colorado Springs, and Grand Junction
- Produced two films: *Achieve With Us* featuring Governor John Hickenlooper and "*I Can Do It: Extraordinary Families Triumph with Disabilities*"
- Sponsors: Colorado Chapters of The Arc, Alliance, arc Thrift, Avenstar, BlueLabs, Rocky Mountain Human Services, Developmental Pathways, 1st Bank, JFK Partners, PASCO, The Legal Center for People with Disabilities and Older Adults, The Resource Exchange, and Stargazers Theatre
- 28 community partners:
Ability Connection Colorado, The Autism Society of Colorado, Colorado Cross Disability Coalition, Colorado Developmental Disability Council, Colorado Fund for People with Developmental Disabilities, Colorado Gerontology Society, Colorado Respite Coalition, Colorado Special Education Advisory Committee, Denver Children's Advocacy Center, Denver Film Society, Denver Film Center, Easter Seals of Colorado, El Grupo VIDA, Entercom Communications, FASD Council, Jeffco Youth Pastor Alliance, Kids Mobility, NOFAS Colorado, Parent to Parent, PADCO, Peak Parent Center, Rocky Mountain Down Syndrome Association, Timberline Church Network, Tri-County Health Department, and Westword
- Almost 1000 people attended the *Achieve With Us Colorado* Film Festivals

Current 2014 Partners

all 2013 partners are committed to partnering again in 2014 in addition to:

- The Candlelight Dinner Playhouse
- The Denver Film Society
- Jewish Family Services
- Phamaly Theater Company
- Stargazers Theatre and Event Center in Colorado Springs

Current 2014 Sponsors

- arc Thrift Stores
- First Bank
- Jewish Family Services / Jewish Disabilities Network
- PASCO
- Stargazers Theatre & Event Center

The film festival committee is in the process of creating a short film featuring fathers sharing their stories of triumph - with hopes of introducing four films to the festival produced by The Arc of Colorado. The priority for the 2014 festivals is to feature locally produced films starring local talent.

We are actively recruiting new members to the committee, event sponsors, and community partners.

Families in Action

The Arc of Colorado with The Association for Community Living in Boulder County, The Arc of Larimer County, and The Arc of Weld County developed a plan to bring together families of young children with intellectual and/or developmental disabilities in a weekend retreat setting to build advocacy skills and create networking connections among families, chapters of The Arc, and other community resources.

The Families in Action Retreat was scheduled for the weekend of October 4, 2013, but due to the devastating floods in Northern Colorado the retreat has been tentatively rescheduled for June 20-22, 2014.

Chapters of The Arc and other sponsors will cover the cost and overhead of the retreat. Approximately 30 families from Northern Colorado will participate in Families in Action at no charge.

The Families in Action program is based on the acknowledgment that parents are the experts on their child and family.

The committee believed that in order to support family growth, the entire family had to be involved. The program involves opportunities for kids to initiate the life-long process of self-discovery and independence through outdoor education, fun, and adventure! Whether they are preschoolers, in grade school, or teenagers - kids have much to say if they are given a chance. Families in Action provides a safe place for kids to express their feelings about living life with an intellectual and/or developmental disability or having a sibling with an intellectual and/or developmental disability. Woven throughout the program are lessons on how kids can become powerful self-advocates and advocates for others.

The Families in Action Retreat is just the beginning. After the retreat families will be included in local chapter activities for on-going support and educational seminars. The goal of the retreat is to create a Northern Colorado network of families to learn together, grow together, and create change for their communities.

We are creating a toolkit for Families in Action to be recreated in other communities and hope to present our program at the 2014 Arc National Convention.



Save the Date

March 5, 2013 Colorado Springs
at the Stargazers Theatre

March 11, 2013 Northern Colorado
at The Candlelight Dinner Playhouse

March 30, 2013 Denver
at The Sie Film Center

Grand Junction To be announced

Marijo Rymer, Executive Director
Cassidy Dellemonache, Associate Director
Heidi Haines, Projects Coordinator
November 09, 2013

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