A THIRTY YEAR HISTORY OF THE DEPRIVATION OF SERVICES TO THE DEVELOPMENTALLY DISABLED POPULATION

IN THE STATE OF NEW MEXICO

SUMMARIES OF

CHAPTERS ONE, TWO AND THREE

AND A PREVIEW OF CHAPTER FOUR

PREPARED FOR

THE INTERIM LEGISLATIVE

HEALTH AND HUMAN SERVICES COMMITTEE

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SUMMARY OF CHAPTER ONE

Beginning in 1990 advocates for Developmentally Disabled New Mexican's convinced the state legislature to limit the growth of Intermediate Care Facilities for the Intellectually and Developmentally Disabled. (ICF's) Since ICF's are in the state Medicaid plan they could not be legally limited under federal law and court precedent.

They did so to force DD recipients into the new DD Waiver program which provided care in the community which was seen as less discriminatory. In the late 1990's they forced the state to close their large institutions at Fort Stanton and Los Lunas. This action forced those with the highest needs into the community waiver program and left lower needs individuals in the ICF's due to the limitation on growth.

One of the conditions of having a community waiver is that it's per person costs must be lower than the states institutions unless they get special permission from the federal government. The instant they closed the large institutions they had to get permission for the waiver cost to exceed the ICF's. This was granted in 2000.

As time passed the understanding of the fact that the special permission was readily granted; was forgotten and the Human Services Department began claiming the waiver was too expensive because it was going to cost more than the ICF's. The number of recipients that can be served in the states ICF's went from about 300 in 1999 to 273 in 2021 while the wait list went from 1264 to over 4600. All this time HSD has been assuring the federal government that the people on the wait list have been given a choice of an ICF according to their rights when they are put on the list.

The advocates hoped the administrations and legislature would do the right thing and take the savings from denying institutional care which was an entitlement and provide it in the waiver. They didn't. They created a 13 year wait list which cost families millions in lost wages and care while at the same time they paid millions in legal fees for 30 years for continually abusing high needs recipients due to inadequate rates in the waiver.

In 2011HSD passed a regulation allowing the department to limit the federally mandated market basket inflation payments. Also the level of care assessment HSD forces them to use was thrown out years ago in the waiver because it did not provide care levels for high medical or behavior need recipients. Currently they can't serve those with high needs.

Now thirty years later thousands of families have been denied care in ICF's. They have been forced to leave the state or split up families for ICF care in other states while they waited for decades for a waiver that may not serve them humanely.

RECOMMENDED IMMEDIATE CORRECTIVE ACTION

1. Implement the central registry for Intermediate Care Facilities in accordance the state law and regulation.

2. Provide persons on the wait list information regarding their entitlement to the services.

3. Contract for a rate study on ICF rates to insure the discrimination in providing services for high need recipients is ended.

4. Remove limitations on expedited placements on the DD Waiver in circumstances where persons on the wait list have emergent need of the residential services they are entitled to.

5. Insure an attorney in the General Council's offices in the Human Services Department reviews and advises their respective Secretaries and Staff of their responsibilities and duties under the Chapter 28 Section 16 A of the New Mexico Human Rights Act and the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 and the department's code of conduct.

6. Insure that the Human Services Department begins providing notice of fair hearing rights in all cases where all entitled services are not being provided to Medicaid recipients in timely manner as required under federal law.

SUMMARY OF CHAPTER TWO

In 2010 the Human Services Department stated concern that the federal Medicaid match rate was returning to a normal rate of about 70% from the two years of the enhanced rate of about 80% the feds provided for recession relief. They floated a 16 million dollar cut to the state's share of the waiver during the interim and received intense blow back and found out it would violate the federal Maintenance of Effort requirement.

For reasons discussed in chapter three, HSD desperately searched for justification to make the cuts. At the same time the Legislative Finance committee was doing an extensive program review on the DD Waivers. They used the measure of "the average cost of a waiver recipient" and applied it to misrepresent New Mexico's unique situation where institutional recipients with the highest needs individuals were forced into the community waiver and the Intermediate Care Facilities were illegally limited. Further the wait list was reduced annually by emergency placements so the population of the waiver was mostly the highest needs individuals. Then to make it appear even more expensive they brought in a contractor who used data from other states who had waivers that did not provide 24 hours care to skew the data even more.

The contractor HSRI had developed a method of using an assessment tool developed by AAIDD and applying a proprietary algorithm to the result which would allow the state reduce or increase budgets across the board to meet the funding instead of needs In 2011 they reduced the budgets 8% and the provider rates 5% in the Supported living portion of the waiver knowing they had a plan in place to avoid loss of federal financial participation.

They did rate study to justify the rate reduction by discarding all the providers cost data and fabricating comparable costs. They did a "Validation" of the whole new system in four days by reviewing 80 cases. They never contacted the case managers to confirm their conclusions. When CMS questioned the small sample they said they would do continual validation. They didn't. They had out of state assessors go around the state to find out which recipients could safely be denied 24 hour care. None of the assessors spoke Spanish and recipients were denied the right to appeal their new budgets and service packages. It went to federal court where they found the recipient's rights were violated and budgets were restored. Rates were not restored. Now most of the waiver programs are on rates that were cut in 2011. CMS requires rates be reviewed every five years the state law requires it every two years depending on funding.

When the court ruled that the participants rights were violated no one from HSD or DOH was reprimanded or fired. Instead they were promoted.

SUMMARY OF CHAPTER THREE

1. HSD and their contractors seriously failed to properly account to Centers for Medicaid/Medicare (CMS) from 2007 to 2011 for payments and services provided in the state's Medicaid program. In 2010 CMS finally withheld funds which created a 103 million dollar negative balance in the state's Medicaid account.

2. In order to make up the 103 million dollars HSD needed to either: 1. Cut services or, 2. Admit they made some huge mistakes and ask for more state funding or, 3. Hold their contractors accountable for their part in the matter and make them pay. They decided to cut services, let their contractors off the hook and cover up the mistakes with the change of administration.

3. The Developmental Disabilities Waiver with it low enrollment numbers, its relatively high individual budgets and complex funding system made it an easy target for budget cuts. The recipients obviously couldn't effectively complain.

4. They embarked on an elaborate discriminatory scheme to cut DD Waiver services, budgets and provider rates to fill the budget hole. Their illegally contrived plan ended up in a federal law suit which found HSD violated the recipient's civil rights. The court restored the services and budgets but not the rates. No one was fired at HSD for the civil rights violations.

5. HSD obstructed the provision of adequate rates for the next several years to keep CMS from questioning the original rate cut and subsequently withholding more money. In the administration's last year they contracted for a study to allow a restoration of rates by the new administration. It has not yet been fully funded.

6. Providers plead with the legislature for years for adequate rates. HSD blocked every attempt. As costs rose providers had to decrease staffing levels, and reduce nursing, staff training and care coordination which resulted in unconscionable rates of abuse, neglect, exploitation and untimely death for those on the waiver.

7. The HSD bureaucrats kept their jobs and got promoted as they sacrificed the health, safety and lives of the state's most vulnerable population for a decade.

8. HSD has falsely claimed for over a decade that New Mexico's cost to serve the DD population is comparatively high because of the average cost of the waiver.

9. The reality is that New Mexico average cost should be the absolute highest in the nation because we have the persons with the highest needs on the waiver and are the only state in the union that illegally denies all the rest of them adequate humane care. When those with no services are added to the average New Mexico is the worst in the nation.

RECCOMENDATIONS

1. Amend the state statutes to make rate studies mandatory in accordance with the federal five year rule and studies mandatory when the legislature increases costs to providers for employee benefits and minimum wages.

2. Amend the state statutes to require reporting of abuse, neglect, exploitation and untimely deaths of recipients of the waivers and the cause of death of persons on the wait list to the LHHS Committee every year.

3. Amend the state statues to require rate studies in the waiver to include the review of the causes of abuse, neglect, exploitation and untimely deaths of recipients of the waivers as well as fair hearings for lack of services.

PREVIEW OF CHAPTER FOUR

Chapter four will explore the effect of the rate cuts in 2010 and how it resulted in a decade of increased abuse, neglect, exploitation and untimely deaths of recipients in the DD Waiver.

It will address the changes in reporting requirements which were apparently designed to mask the increases in cases due inadequate rates.

It will address the removal of independent oversight by Adult Protective Services in cases of increased abuse, neglect, exploitation and untimely death in the DD Waiver which removed the protections of state Residential Abuse and Neglect Act for recipients of the DD Waiver. This allowed perpetrators to continue the behavior in other agencies by reducing referrals to police or local district attorneys.

From 2015 to 2020 there were 7915 complaints of abuse neglect and exploitation in the waiver. 2999 cases were confirmed on 1792 victims. The major causes were lack of supervision, lack of training, inadequate health care plans and medication error all which are attributable to inadequate rates.

It will address how the misinformation campaign to cover up the malfeasance and contractor error at HSD resulted in the Legislature being misled as to the actual comparative cost of serving the developmental community and the continued misinformation was designed to delay new rates studies which would raise concerns at CMS.

It will address a subsequent misinformation campaign designed to limit placing new recipients on the waiver due to concerns that it would cause levels of abuse, neglect and exploitation that could not be contained or cause the providers to have to place themselves on moratoriums avoid bankruptcy. This misinformation campaign was the claim that the waiver did not have the capacity to take more people and that people were receiving adequate services from Medicaid.

The most heinous of these representations is that Developmentally Disabled persons on the wait list are receiving therapy after they graduate from school. The maintenance therapy that DD people need is not covered under regular Medicaid and is ONLY available from a waiver, an intermediate care facility or the Centennial care community benefit which has no provider directory or network for such services.

RECOMMENDAITONS

1. Have the LHHS committee draft and endorse a memorial to make the LHHS a permanently staffed committee like the Legislative Education Study Committee.