Therapies on the DD and Mi Via Waivers

1) Medical Therapies (PT,OT,SLP) are provided universally across programs Nationwide as they decrease unnecessary medical decline, unnecessary suffering, unnecessary pain, and unnecessary death. They also increase communication, mental health, quality of life, independence, and overall health. (see page 2-3)

2) The cost of "Therapies" on the DD waiver/Mi Via have gone from 10% of the total costs when average cost was $71,000 a person in June 2009 to 5.7% of total cost when the average cost per person has gone to $78,000 a person in 2017. (page 3 bottom).

3) During June 2009 the cost to provider these "Therapy" services was 25 million dollars for 3,777 enrollees. In 2018 it cost 20.5 million dollars to provide these services to approximately 4700 people. And the hourly rates paid to the "Therapists" have gone up significantly is most regions in New Mexico (page 3).

4) DD Waiver (only) costs for medical therapies (SLP, PT, OT) have gone from 5.7% of total waiver costs in 2011 to about 4.6% in 2017 (based on 2011 split of costs). During this same time frame the cost of the waiver has gone up about $6,000 a person. These Medical Therapies are not driving costs. (see page 4).

5) 185 of 185 or 100% of programs where adults with developmental disabilities get Long Term Care services (LTC) provide LTC/Habilitative options for Medical Therapies (SLP, OT, PT). Any suggestion that these programs are not universal across all States is FALSE. How they are funded varies greatly across States. (see page 6 and add. 1)

6) The actual cost, to NM, of all therapies (medical and behavioral) for both the DDW and Mi Via program in FY 2017 was about $4.9 million. Approximately 3.2 million for Medical Therapies (OT, PT, SLP) and 1.6 million for Behavioral services. This number comes from taking off federal Medicaid match and accounting for gross receipts tax generated by these services. (See page 9).

7) In 2015 DDSD did a Survey of 6,402 people in Waiting list for DD waiver/Mi Via. The 474 respondents were asked what services would be most helpful for them. The results were: 1) Rec Therapy 2) Speech Therapy 3) Respite 4) Occupational Therapy 5) Physical Therapy. These are the services people are wanting to see when they finally get a waiver allocation. (see page 10). Or while waiting for waiver allocation.

1) Medical Therapies are provided universally across programs as they decrease unnecessary medical decline, unnecessary suffering, unnecessary pain, and unnecessary death. They also increase communication, mental health, quality of life, independence, and overall health.

Medical therapists work on numerous things from electronic devices for communication (AAC) to positioning in wheelchairs. For this paper we have decided to focus just on how therapists help reduce preventable death. DDSD NM presented the top causes of preventable death in the Developmental disabilities community as: Bowel Obstruction, GERD, Aspiration, Dehydration, Seizures. (please see attached document "THE FATAL FIVE")

Aspiration. Aspiration is food or liquid going into the lungs instead of stomach. Speech Therapists normally work on diagnosis of disorder and the following items to reduce aspiration: exercises to increase food control, adaptive techniques such as head positioning, food/liquid modifications, and staff training. They are assisted by OT's who work on getting appropriate adaptive equipment, independent eating, and positioning. PT's also assist by getting patient strong enough to support themselves during meals, ensure proper positioning during meals, and ensuring appropriate equipment available (wheelchair tables, standers, etc).

GERD (reflux) can destroy delicate tissues resulting in GI bleeding, cause aspiration, increase chances of esophageal cancer. SLP's can assist in getting appropriate proportion size, appropriate food consistencies, appropriate eating/swallowing techniques, assist with communicating choices for low GERD food choices. OT's can ensure appropriate eating equipment, appropriate positioning, and in assisting people/staff to make healthier eating choices. PT's can assist with weight maintenance, increase activity levels safely, assist with positioning, weight bearing, and appropriate equipment is available all reducing GERD and effects of GERD.

Dehydration is most common among those with swallowing problems and neurological problems. People who have difficulty swallowing are far more likely to refuse liquids or get inadequate liquid. The same treatments listed for GERD and Aspiration above are very similar to what therapists do for dehydration.

Bowl Obstruction is caused by lack of movement, lack of weight bearing, poor diets, and lack of fluid. People with severe impairments have difficulty finding movement activities that are safe and able to be done on a regular basis. PT's and some OT's can assist in finding safe movement and weight bearing activities to reduce constipation. OT's can assist is proper positioning, toileting routines, appropriate bathroom equipment,

hydration, and diet. SLP's can assist with getting adequate safe hydration that doesn't cause aspiration, safe intake of high fiber foods, and choice making to help people select healthy foods they prefer.

Another top cause of preventable death that NM has done well in preventing is bed sores. These bed sores occur when too much pressure is put on one point in the body causing open wounds. The pressure is caused by inappropriate equipment and staying in one position to long. Many people with neurological disabilities regularly develop these bed sores causing excruciating pain and even death. These sores can leave people bed bound for months as they heal. PT's and OT's collaborate to ensure appropriate equipment (wheelchairs, beds, chairs, pads, mattresses, bathing equipment, and transfer devices are available)is available. PT's and OT's also ensure adequate movement and repositioning occurs to ensure bed sores do not develop.

All three medical therapy disciplines (PT, OT, SLP) work together with nursing staff, physicians, dieticians and direct care staff to greatly reduce these causes of death. Much of what therapist do is evaluate, collaborate, obtain appropriate equipment, create treatment plans, monitor progress, and train staff on these plans. On-going training and monitoring are required for the success of these plans.

Therapist also assist people in developing: independence in daily living, skill development, independent movement, communication, communication devices, reducing affects of chronic disease, balance, and overall health. A dissertation could be written about the many treatment activities therapist do within the HCBS waivers, but we have decided to limit it for this paper. We believe there is a reason all 50 states choose to provide this "optional service" in every setting.

2 and 3. The cost of "Therapies" on the DD waiver/Mi Via have gone from 10% of the total costs when average cost was $71,000 a person in June 2009 to 5.7% of total cost when the average cost per person has gone to $78,000 a person in 2017. Numbers from ACQ sub-committee presentation by Mikki Rogers (DDSD director June 2009) and from Legislative Finance Committee 2018.

Date	People Served	Total cost of Therapies	Total Cost per person
June 2009	3777	25 million	$71,000
2017 (2018 report)	4700 approx	20.5 million	$78,000

(4) Waiver costs for medical therapies (SLP, PT, OT) have gone from 5.7% of total waiver costs to about 4.6% in 2017 (based on 2011 split of costs). During this same time frame the cost of the waiver has gone up about $6,000 a person. A Comparison of FY 2011 data cited from the NM DDSD Resource Allocation Project Report prepared by Burns and Associates 2/17/2012 and FY 2017 information taken from the prepared by the NM LFC Program Evaluation Unit data is provided in the following table.

	**Information Taken From NM DDSD Resource Allocation Project Prepared by Burns and Associates 2/17/2012					Information taken from Report #18-06 to LFC		
Service	FY 2011 Expenditures	FY 2011 Expenditures for Medical Therapies Only	FY 2011 Total Cost Per Service Type		FY 2011 Service % of total Therapy Costs	FY 2017 Expenditures per service	FY 2017 Estimated Cost per service based on 2011 percentages	FY 2017 Estimated Cost for Medical Therapies
Behavior Support Consultant	$ 6,813,476.00					Breakdown Not available		
Behavior Support Consultant-Clinic	$ 1,543,917.00		BSC	$8,357,393.00	36%	N/A- no longer available	$ 7,200,000.00	
Occupational Therapy	$ 3,714,084.00	$ 3,714,084.00				Breakdown Not Available		
OT- Clinic	$ 308,540.00	$ 308,540.00				Breakdown Not Available		
COTA	$ 31,627.00	$ 31,627.00	OT/COTA	$4,054,251.00	17%	Breakdown Not Available	$ 3,400,000.00	$ 3,400,000.00
Physical Therapy	$ 3,799,865.00	$ 3,799,865.00				Breakdown Not Available		
PT-Clinic	$ 270,837.00	$ 270,837.00				N/A- no longer available		
PTA	$ 5,999.00	$5,999.00	PT/PTA	$4,076,701.00	17%	Breakdown Not Available	$ 3,400,000.00	$3,400,000.00
Speech Therapy	$ 6,219,431.00	$ 6,219,431.00				Breakdown Not Available		
SLP-Clinic (assess)	$ 718,089.00	$ 718,089.00				N/A- no longer available		
SLP-Clinic	$ 456.00	$ 456.00	SLP	$ 6,937,976.00	30%	N/A- no longer available	$ 6,000,000.00	$ 6,000,000.00
Total	$ 23,426,321.00	$15,068,928.00				$ 20,000,000.00	$20,000,000.00	$12,800,000.00
Total DDW Expenditures	$ 263,313,429.00	$263,313,429.00				$274,400,000.00		
% of Therapies	8.89%	5.72%				7%		4.66%
						% is per LFC report 7/20/2018		

-Cost % for FY 2017 are based on the % breakdown of cost per therapy service in 2011. We do not have current breakdown of service costs, just total cost. So estimated cost breakdown on Burns rate study data.

-Overall costs for ALL therapies have decreased from 8.89% in 2011 to 7% in 2017 on the DDW. This includes Behavioral and Medical Therapy costs.

-Total combined program costs for Mi Via and DD waiver attributed to all therapies was 5.7% in FY 2017. To include Behavioral Services and Medical Therapies.

-Since 2011 Medical Therapy and Behavioral reimbursement rates have increased for about ½ the people on the waiver receiving services in Rural area. This indicates that Medical Therapies and Behavioral services have an even greater drop in utilization from 2011 to 2018 than suggested the numbers listed above.

As demonstrated above the cost of therapies are not driving costs. There was a reduction in therapy costs in 2014 due to the implementation of the SIS. The SIS resulted in many people losing many therapy services all together. The forced reduction in services was found to be a violation of constitutional rights of DDW participants. It also resulted in another costly law suit the State needed to settle. It also resulted in people with Developmental Disabilities getting a fraction of the medical and mental health care received in other States (see item number 3 above).

Since 2011 it appears several counties are now receiving at least 1 therapy services that previously received none. Therapy availability has probably gone up slightly while total costs of Medical Therapies have gone down.

It has been suggested that Therapist can get however many hours they want. And this is a partially true Statement. All hours have to be justified and DDSD has a form that recommends available units. It appears Therapist average about 35 hours a year to include all care plans, meetings, paperwork, and direct contact. Date presented by DDSD suggests this is very stable over time.

5) Availability of Long Term (Habilitative/Maintenance) Medical Therapies (OT, PT, SLP) and Behavioral Supports/Mental Health

STATE	HCBS/ Behavioral	HCBS PT, SLP, OT	Institu tional 2016 (# of people) Med Therapy	ICFMR (# of people) 2016 Med Therapy	Nursing Home 2016 (# of people)	Other
1.Alaska	Yes	Yes (multiple ways of getting)	NA	Yes (54)	NA (0)	Long term care & Hospital/Rehab
2. Alabama	Yes	Yes	NA	Yes (788)	Yes (935)	
3. Arizona	Yes	Yes (both)	Yes	Yes (33)	Yes (50)	
4. Arkansas	Yes	Y (consultation)	Yes	Yes (925)	Yes (638)	
5. California	Yes	Yes	Yes	Yes (1099)	Yes (1,112)	
6. Colorado	Yes	Yes (state plan)	Yes	Yes (161)	Yes (64)	
7. Connect	Yes	Yes (State plan)	Yes	Yes (242)	Yes(339)	
8. Delaware	yes	yes	Yes	Yes (58)	NA (0)	
9. District of C.	Yes	Yes	NA	Yes (1)	Yes (6)	
10. Florida	Yes	Yes	Yes	Yes (1291)	Yes (285)	
11. Georgia	yes	Yes	Yes	Yes (11)	Yes (972)	
12. Hawaii	Yes	Yes (both?)	NA	Yes (7)	Yes (68)	
13. Iowa	Yes	Yes (State plan)	Yes (1090)	Yes (753)	Yes (670)	
14. Idaho	Yes	yes	Yes (117)	Y	Yes (113)	
15. Illinois	Yes	Yes	Yes (4364)	Yes (7543)	Yes (151)	
16. Indiana	Yes	Yes	NA	Yes (45)	Yes (1568)	
17. Kansas	Yes	Yes (state plan)	Yes	Yes (?)	Yes (121)	
18. Kentucky	Yes	Yes	Yes (278)	Yes (24)	Yes (736)	
19. Louisiana	Yes	yes	Yes (?)	Yes (?)	Yes (598)	
20. Maine	Yes	Yes	NA	Yes (124)	Yes (10)	
21. Massachusetts	Yes	Yes	Yes (?)	Yes (?)	Yes (267)	
22. Maryland	Yes	Yes	Yes (197)	Yes (234)	Yes (279)	
23. Michigan	Yes	Yes (state plan)	NA	Yes (387)	Yes (411)	
24. Missouri	Yes	yes	Yes (420)	Yes (940)	Yes (1148)	
25. Mississippi	Yes	Yes	Yes (?)	Yes (?)	Yes (381)	ICFMR 711 in 2015 Instit 1778 in 2015
26. Minnesota	yes	Yes	NA	Yes (422)	Yes (155)	
27. Montana	Yes	Yes	Yes (300)	Yes (42)	Yes (120)	
28. Nebraska	YES	Yes	Yes (338)	Yes (163)	Yes (177)	
29. Nevada	Yes	Yes (state plan)	Yes (192)	na (0)	Yes (112)	
30 New Hampsh.	Yes	Yes see below	NA	Yes (10)	Yes (108)	
31. New Jersey	Yes	Yes	Yes (2329)	Yes 812)	Yes (856)	

32. New Mexico	Y	Y	Na	NA	Yes (81)	
33. New York	Yes (IPSIDD)	Yes (IPSIDD)	Yes (1380)	Yes (18,463)	Yes (1581)	
34. North Carolina	Y	Y	Yes (?)	Yes (?)	Yes (805)	
35. North Dakota	Y	Y state plan	Yes (106)	Yes (409)	Yes (122)	
36. Ohio	Y	Y	Yes (3525)	Yes (2546)	Yes (1406)	
37. Oklahoma	Y	Y	Yes (882)	Yes (481)	Yes 1340 in 2015	Nursing Home didn't file 2016
38. Oregon	Y State Plan	n State Plan Maintenance	Not avail.	Yes (174)	Yes (161)	
39. Pennsylvania	Y	Y	Yes (2063)	Yes (485	Yes (2344)	
40. Rhode Island	Y	Y (see below)	Yes (25)	Yes (188)	Yes (6)	
41. South Carolina	Y	Y	Yes (666)	Yes (855)	Yes (265)	
42. South Dakota	Y	Y	Yes (192)	Yes (661)	Yes (87)	
43. Tennessee	Y	y	Yes (131)	Yes (641)	Yes (567)	
44. Texas	Y	Y	Yes (3368)	Yes (502)	Yes (2492)	
45. Utah	Y Ext. State plan	Y Extended State Plan	Yes (762 in 2015)	Yes (74 in 2015)	Yes (34)	
46. Vermont	Y	Y	?	?	?	
47. Virginia	Y	Y	Yes (534)	Yes (990)	Yes (1657)	
48. Washington	Y	Y	Yes (700)	Yes (27)	NA (0)	
49. West Virginia	Y	Y	Na	Yes (425 in 2015)	Yes (213)	
50. Wisconsin	Y	Y (both)	Yes (774)	Yes (13)	Yes (22)	
51. Wyoming	Y	Y	Yes (?)	Yes (?)	Yes (27)	
Total offered	51/51	51/51	39/39	48/48	48/48	

(NA means this setting was not found as an option in the State).

Results of Research

186 of 186 or 100% of programs where adults with developmental disabilities get Long Term Care services (LTC) provide LTC/Habilitative options for Medical Therapies (SLP, OT, PT). Any suggestion that these programs are not universal across all States if FALSE. How they are funded varies greatly across States.

After the Program Evaluation Unit from the Legislative Finance Committee came out we felt some information should be clarified. So we researched all 186 settings that people with Developmental Disabilities receive services in Nationwide. The setting we found were HCBS (similar DD waiver and Mi Via waiver), Institutions (all closed in NM), ICFMR (couldn't find data on any currently operating in NM), and Nursing Homes (probably worst option).

186 out 186 setting available for care offer long term habilitative Medical Therapy care for Developmentally Disabled Adults

100% of States offer this optional service (SLP,OT,PT) to people with developmental disabilities, on HCBS waivers, through various funding sources. Most do through HCBS waivers and the rest do through State plans.

100% of States offer Behavioral/Mental health services in the community to people with developmental disabilities in community settings.

Many States seem to have no caps on how many Medical therapy hours a year can be obtained. NM therapy agencies have repeatedly suggested different ways to control costs and limit overall costs. Several suggestions have been partially adopted by DOH over the last 10+ years.

Some interesting findings in research

-Alaska provides in community through State Plan and through Intensive Medical Treatment Category on HCBS waiver.

-Colorado under state plan "Habilitative Care" and was another trial plan with additional services under waiver.

-Connecticut- Must get prior approval if more than 9 visits for ID/DD State Plan for LTC. No limits once prior authorization obtained.

-Iowa- No limits on Medical therapies for any Medicaid program covered

-Minnesota does provide under the category of Specialist Support Services or Specialist Services. Appears much more limited than other States? No habilitative care under State Plan.

-New Hampshire: Under specialty services. Can also get home health with self-direction program.

-North Dakota- 30 visits per year basic with additional units available upon request. Maintenance care available.

-Nevada offers LTC Medical therapies "maintenance therapies" to most people on Medicaid.

-Rhode Island is under one 1115

-Utah through extended state plan. Found in waiver application

<u>Some of the Sources used for this Data:</u>

-Burns rate study 2011

-2018 LFC Program Evaluation Units report on Developmental Disabilities and Mi Via Waivers

-Federal Government Medicaid Web Sites

-State Government Medicaid Web Sites

-Truven Health Analytics and University of Wisconsin

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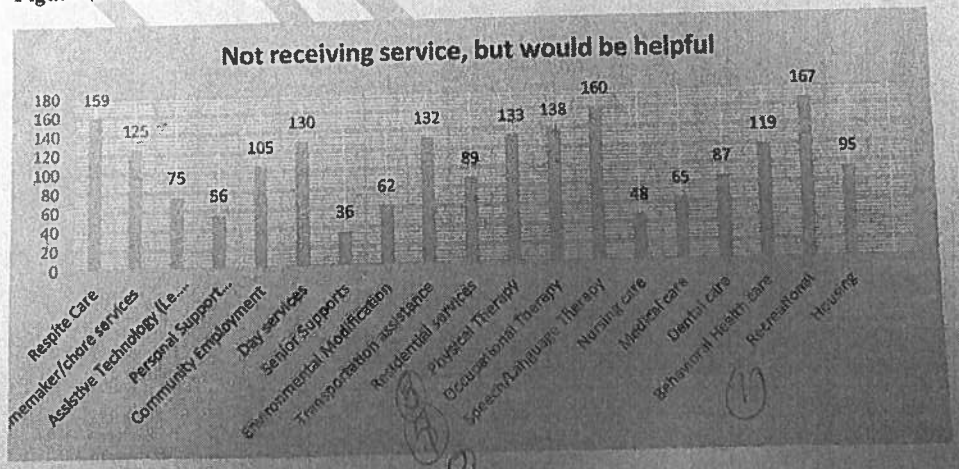
6) The actual cost of therapies to NM is about Total Cost of Therapies for both the DDW and Mi Via program in FY 2017 was $4.9 million with federal Medicaid match. Approximately 3.2 million for Medical Therapies and 1.6 million for Behavioral services.

-Total Costs	20.5 million for Mi Via and DD wavier
-Federal match (72%)	-14.6 million dollars
-Cost at Legislative level	
- Sales tax 8% of 20.5 x 72% Match	-1 million dollars (approx. Majority of services provided by for profit companies)
-Cost to NM	4.9 million dollars per year (approx.)
-Cost of Behavioral (approx.)	1.6 million dollars per year (approx.)
-Cost of Medical Therapies (approx.)	3.2 million dollars per year (approx.)

It was suggested that Physical Therapy services are driving the cost of the waiver. Physical Therapy is traditionally about 1% of the cost of the cost of Mi Via/DD waiver total costs. How a service that is 1% of a total budget is driving the cost of a budget is difficult for us to understand. We look forward to updated numbers.

In terms of capacity building, the survey results show the highest percentage of respondents indicated they would find respite, speech/language therapy and recreation helpful for them. Further analysis will be conducted to determine the specific needs and resources the respondents felt would be helpful to them.

Figure 8: Tell us what systems of supports and/or services you feel would be helpful



THE FATAL FIVE

The Fatal Five refers to the top five disorders linked to preventable deaths of individuals in congregate care settings or in community based residential settings. While the issues can differ in order of frequency depending on the population being represented, the five conditions most likely to result in death or health deterioration for persons with Intellectual and Developmental disabilities are:

■ Bowel Obstruction ■ GERD ■ Aspiration ■ Dehydration ■ Seizures

Bowel Obstruction is the most common cause of preventable death in community settings. The most important root cause of bowel obstruction is the use of multiple drugs with constipating side effects. Add to this the fact that most of us have dietary habits that contribute to the problem, chief among them, diets that are low in fiber and adequate fluids. Ironically, medications intended to improve elimination often place the individual at higher risk for impaired bowel function. Adequate active movement or exercise is also important to the gut. Controlling these factors, along with training caretakers to recognize the signs and symptoms of bowel problems at the earliest moment can greatly reduce occurrences of death from bowel obstruction.

Gastroesophageal reflux disease (GERD) is the backing up of stomach contents, including acid, into the esophagus. GERD is undiagnosed in the majority of persons, including those without disabilities, until major harm has been done to the bottom of the esophagus. Medications that cause constipation also contribute to GERD. Individuals who are overweight, particularly when they carry excess weight around the abdomen or wear clothing that is too tight have a higher risk of GERD. Ill-advised dietary choices, immobility and improper positioning also contribute greatly to the incidence of GERD. As this disorder continues without treatment discreet or frank aspiration, life-threatening GI bleeding and esophageal cancer become increasingly common.

Aspiration is the most common cause of death in institutional settings, including nursing homes and large group care settings for persons with IDD. Aspiration often begins subtly and damages increasing portions of the lungs. Aspiration pneumonia is a common discharge diagnosis following hospitalization. As the person's respiratory status becomes compromised feeding tubes, which carry their own increased risks, are often utilized. Other factors which may lead to aspiration are poor body positioning, particularly in individuals who cannot control their own movements well, and behavioral issues related to eating.

Individuals who do not swallow well are particularly likely to refuse fluids or indicate fear when they get them, often resulting in dehydration. Dehydration is also likely when staff or family try to restrict fluids to prevent incontinence, not realizing that lack of fluids can contribute to constipation and increased seizure frequency, not to mention drug toxicity and other health problems.

Seizure deaths can occur from drug toxicity or from uncontrolled seizures. SUDEP, or sudden unexplained death in epilepsy, occurs on a fairly regular basis and for reasons that medical science has yet to explain. Life expectancy for persons with active seizure disorders has shown to be up to 10 years less than those without epilepsy.

Must-see Webinar ! THE FATAL FIVE: Preventing Preventable Deaths in Community Settings Presented by Karen Green McGowan, RN, CDDN Health Risk Screening, Inc. and New York State Rehabilitation Association (NYSRA) collaborated on a series of free, hour-long educational webinars presented by Karen Green McGowan. Here is a link to a recorded webinar, "The Fatal Five": Preventing Preventable Deaths in Community Settings. The webinar received outstanding feedback and numerous agencies have begun using the presentation as part of staff training. The information covered in the webinar is applicable to clinical, administrative and program services professionals. Watch the webinar, use the information and feel free to forward the above link to any colleagues you feel would be interested in or benefit from the information presented.

If anyone has questions or would like any additional information please contact Danny Palma at

dtsdanny@gmail.com

Kerry@directtherapyservices.com