POSITION PAPER:

"CONSUMER / PARTICIPANT DIRECTION"

HAS always been a Integral, fundamental and "STATUTORY" part of the Federally Funded

1915c HCBS waiver program.... ESPECIALLY AS IT RELATES TO THE "SERVICE" OF:

Personal Assistance Services – (PAS).....

By its definition IT HAS TO BE

CONSUMER / PARTICIPANT DIRECTED

PREFACE

It is a losing proposition for ANY State or ANY State Actor to assert that they CAN design, re-design and then amend a program for the most part is funded with federal dollars. The program in discussion is that of the 1915c Home and Community Based Support (HCBS) waiver services.

Each state that applies for and is granted these federal dollars MUST establish a SERVICE DELIVERY SYSTEM that affirmatively addresses and supports several mandates, assurances and fundamental principles (THE INTENT) of the federal program.

In this particular discussion there are several Laws, Acts, Statutes both Federal and State that clearly outline the 1915c HCBS waiver program.

It is true that the State (Pennsylvania) had enormous latitude to design a waiver program that fits into its operating system, as long as COMPLIANCE with these mandates and assurances are maintained.

It is important that the reader understand that a government is made up of both elected, appointed and hired Managers, Directors and Department Heads.... All Administrators that may or may not be in a position of accountability because of the complexities of many governmental structures. Similarly there are other political forces at play (special interest and lobbying groups) competing for dominance, recognition and /or for survival. Pennsylvania is no different.... This paper begins with a brief narrative of an evaluation report (MedStat (2006)) commissioned by the State to evaluate efficiencies and structural issues within it's (THEN), Long Term Living system-(LTL).

The reader should also understand that the LTL system evaluated THEN was and had been in place since 2000... the beginning of the 1915c HCBS waiver program in Pennsylvania. Moreover the changes recommended in this report were for the most part NOT starting to be executed until 2010. That said (2000 – 2010) ALL PROVIDERS providing 1915c HCBS waiver services to the TARGET POPULATION OF (ADULT INDIVIDUALS WITH PHYSICAL DISABILITIES BETWEEN 19- 59 YEARS OF AGE) operated as Agencies With Choice (AWC) (Discussed later) service delivery model .... AND THERE WERE/WAS NO OTHER "TYPE" OF PROVIDER SERVICE DELIVERY MODELS available to participants/Consumers with physical disabilities receiving HCBS waiver services through the States LTL system.

That being said, ANY argument or justification or ANY tactic willingly or unwittingly executed regardless of the manner in which that creative directives were written or unwritten or in many instances only verbally articulated by those empowered individuals within the LTL system that DENIED "FULL and EQUAL ACCESS" as statutorily and historically stated in the: Americans With Disabilities Act (1990), the "OLMSTEAD DECISION (1999), the Civil Rights Act (1964), Pennsylvania's own Attendant Care Act (1986), CMS FINAL REPORT (2016) and the 14th Amendment of our Constitution.

Part (1) one of this paper uses the MedSTAT Report (2006) to give witness to and digestion of the dysfunction and disconnect of the LTL system from "OTHER peoples eyes" at the time.

Part (2) two of this paper focuses on the legal evolution of STATUTORY EMPOWERMENT of those individual participant/consumers authorized and approved to receive services "SERVICES" through these public accommodations /services and the direct connection to show and why 1915c HCBS waivers services, specifically the "SERVICE" of Personal Assistant Services (PAS) are and that the service of PAS can only be provided, REGARDLESS OF THE "TYPE" OF SERVICE DELIVERY MODEL, under and in the manner that historically is referred to as "CONSUMER CONTROL, CONSUMER DIRECTION and PARTICIPANT DIRECT.

Part (3) three of this paper focuses on the Department of Human Services (DHS) action to transition MANAGEMENT functions of the current 1915c HCBS Community Health Choice HCBS waiver (2018) under a system that is managed by three (3) Managed Care Organizations (MCO's) structure was/is a "intensely suggested" option made to Pennsylvania back in 2006 .... before the Federal Government/CMS took "severe action". Still to this day, the administration of 1915c HCBS waiver(s) (through OLTL) and the manner in which the "SERVICES" are administered (through the (3) Managed care Organizations (MCO's) shows that there ae STILL lingering "INSTITUTIONAL BIASES" or "vestiges of discrimination" and all that it entails still demonstrated on a daily basis.

"The PROGRAM" of 1915c HCBS waiver(s) and the provision of its waiver "services" continue to be "MIS REPRESENTED" willfully and with hard coded "Institutional Biases" by those who " ARE SUPPOSSEDLY IN THE KNOW" . Although the State MUST retain its administrative oversight, it (THE STATE) continues to fail to address the many structural issues, ambiguous and craftfully worded "WAIVER" and "SERVICE PROVISION" descriptions and the use of "double talk"... that unfortunately MIS-REPRESENTS What and How HCBS services are and how they are supposed to be delivered. These mis-representations were common place under the previous system... and now many of those supposedly "IN THE KNOW" individuals are either part of the NEW MCO construct and what should be the most obvious system disconnect is that the historical function and structure of the MCO's.... to managing "MEDICAL care and "SERVICES" .... The systems employed are more aligned with services (IN: TYPE: SCOPE: FREQUENCY: AMOUNT and DURATION) that ARE NOT CONSISTANT with what HCBS waiver services are ... specifically as it relates to the provision of the "SERVICE" of Personal Assistance Services (PAS).

POSITION

LET ME BEGIN BY MAKING THIS ASSERTION ON BEHALF OF ALL THOSE INDIVIDUAL PARTICIPANTS/CONSUMERS WHO HAVE BEEN DETERMINED BY THE STATE AS "ELIGIBLE" TO RECEIVE the "SERVICE" of Personal Assistance Service (PAS) under Pennsylvania's 1915c Home And Community Based waiver Community Health Choices waiver that was APPROVED BY CMS- Centers for Medicaid Services, in 2018.

The approved waiver (originally called the COMMCARE waiver) WAS AMENDED and renamed the Community Health Choices – CHC waiver. The CHC waiver through its amending COMBINED (3) three waivers into a single waiver. The waivers that were COMBINED were: the AGING waiver, the INDEPENENCE waiver and the ATTENDANT CARE waiver. The "TARGET GROUP" of this waiver now included (correctly so) ... ADULTS AGED 65 and OVER .... And ADULTS between the ages of 19 -64 who have PHYSICAL DIABILITIES.

From the moment a Consumer/Participant asserts their desire to receive Home and Community Based Support waiver services INSTEAD OF receiving "NO" services ... ACKNOWLEGES THEIR WILLINGNESS TO ACCEPT THEIR RESPONSIBLE TO DIRECT/CONTROL "SOME OR ALL" OF THEIR SERVICES. AND THE STATE IS **OBLIGATED** TO ENSURE SUPPORTS ARE IN PLACE TO ASSIST THAT INDIVIDUAL IN REALIZING THAT DESIRED INDEPENDENCE IN THEIR OWN HOME AND TO THE GREATEST EXTENT POSSIBLE , AS IF THEY HAD NO PHYSICAL DISABILITY.

ALL of the "SERVICES" offered through this waiver **MUST BE EQUALLY ACCESSABLE and PROVIDED (AS DEFINED IN THE WAIVER)** to ALL individuals who encompass the TARGET POPULATION of individuals APPROVED to receive HCBS services under this 1915c HCBS waiver. (14th Amendment)

ANY 1915c HCBS waiver as per the 1915c HCBS Application, Instructions and Technical Guide version 3.5 APPROVED BY CMS.... MUST HAVE SOME DEGREE AND/OR SERVICE DELIVERY VEHICAL/MODEL THAT ENSURES/AFFORDS EACH INDIVIDUAL IN THE TARGET GROUP THE ABILITY TO "CONTROL/DIRECT" **"SOME OR ALL"** OF THE "SERVICES" uniquely identified in their respective Individual Service Plan(s).

"SOME OR ALL" is the federal mandate AND IS NOT A SITUATION THAT CAN BE ALTERED using some form or process, condition or qualification to justify or mutating the understanding of the ability of each PARTICIPANT to SELF-DIRECT/ PARTICIPANT DIRECT "SOME OR ALL" OF THEIR "SERVICES". **The decision to manage "SOME OR ALL" is SOLEY the decision of each individual consumer/participant to make and based on their particular ability and life situation at that time.**

SIMILARLY, the AUTHORITIES empowering each individual approved to receive services under this waiver ARE "EQUALLY" granted to ALL Consumers/Participants WITHOUT condition or qualification as articulated in each "SERVICE" definition.

THE AUTHORITIES granted to every individual approved/authorized to receive HCBS under the 1915c CHC waiver are:

"EMPLOYER AUTHORITY" and "BUDGET AUTHORITY" (As HARD CODED: defined by CMS and not modified to sound the same and include IF /THEN conditions.

The "SERVICE" in question (for purposes of this paper) is that of **Personal Assistant Service- (PAS).**

The authorities stated above are clearly defined and clearly articulated. "service" of PAS is similarly clearly defined and articulated.

ANY **attempt, process, pathway or interpretation** that puts forth the notion that a consumer ELECTS TO RECEIVE a **"SEPARATE BUT EQUAL "** ... form of the "SERVICE" called Personal Assistant Service (PAS) as defined ..... No matter how one may word, justify or define or describe the process... is a violation of that individual consumers/Participants: Civil Rights, as cited through the lens of the Americans with Disabilities Act, Olmstead Decision, the 14th AMENDMENT (EQUAL PROTECTION CLAUSE) OF OUR United States CONSTITUTION, and PENNSLVANIA's own 1986 Attendant Care Act.

As indicated in the title of paper the focus is on the INDIVIDUAL participants Right to Control / Direct **"SOME OR ALL"** of THE "SERVICE" referred to as: Personal Assistance Service-**PAS.... SPECIFICALLY AS ADMINISTERED THROUGH PENNSYLVANIA's OFFICE OF LONG TERM LIVING-(OLTL) 1915c HCBS waiver: CHC waiver (2018)**

This paper is NOT suggesting that the current situation is the result of intentional bias or the covert act or actions of those serving today. But this paper is asserting that the current situation OR EXPRESSED UNDERSTANDING **OF WHAT AND HOW** the 1915c HCBS waiver and its "SERVICES" are supposed to be provided is a DIRECT result of a host of incompetence's ranging from lack of oversight, to a lack of "WILL" to address and refute the INSTITUTIONAL BIASED decisions, mis-conceptions and actions as well as power play by both individuals and businesses (PROVIDERS and Special Interest Groups) in their attempts to benefit from and/or capture the almighty dollar... at the expense of ours States most AT-RISK citizens.

IT IS DISCRIMINATION by DENYING anyone "FULL and EQUAL ACCESS" to the same "SERVICES".... (in the SAME manner and Scope) as provided to "OTHERS" similarly determined eligible BY THE STATE to RECEIVE THE EXACT SAME SERVICES AS DEFINED WITHIN THE SAME WAIVER and offered through the same public entity (OLTL) or it's STATE ACTOR (the MCO's).

PART ONE:

The Medstat Evaluation:

"Home and Community Based Services Reform and rebalancing Feasibility Analysis"
Report submitted: March 24 **2006**. By Medstat.

IN BRIEF: As cited: in the INTRODUCTION of this report:

In July 2005, the (THEN) named Department of Public Welfare (DPW) contracted with Thomson MEDSTAT to evaluate Pennsylvania's Long Term Living programs , with special emphasis on the current structure of the States Medicaid Home and Community Based Supports (HCBS) waiver programs.

The objective was to Identify problems and offer recommendations on financing, administration and the delivery of HCBS waiver services.
The Methods used by Medstat in its evaluation included:
MEDSTAT gathered information from various sources regarding The various HCBS waiver programs through interviews with management and operational staff at;

DPW
Dept. of Aging (PDA)
The Governors Office of Health Care Reform (GOHCR)
DPW's Advisory Council for HCBS and
The Stake Holders Planning Team

As well as interviews with LOCAL managers and Support Coordinators from several Agencies on Aging (AAA), Attendant Care Agencies and administrative entities and enrollment agencies for the Community Services Program for Persons with Physical Disabilities (CSPPPD). **ALL personnel were selected by DPW.**
Overview of Findings:

1- The Demographics of Pennsylvania's AGED population (65 and older) was at the time the second highest of all states according to 2000 census. Growth rates in this population were so high that comparative analysis suggested that other States WOULD NOT EXPERIENCE these numbers for another 10-15 years.
2- As a result, **Nursing Home utilization** rates per 1000 over the age of 65 were higher than the national average across all states, However **Institutional utilization** (ICF/MR rates were lower than the national average.
3- At the time Pennsylvania operated (11) HCBS waiver programs serving a variety of TARGET GROUP Populations... The national average per State was 5.7.
4- Of the 11 HCBS waivers: (Again this Report was published in 2006)
   - **6 were administered through OLTL,**

   OBRA Waiver (Access is gained through 3 regional enrollment agencies)
   Commcare waiver (Access is gained through 3 regional enrollment agencies)
   Independence Waiver
   Attendant care waiver

Act 150/Attendant Care (State Funded Program)
Elwyn Waiver (Hard of Hearing) Access is through Delaware County Area Agency on Aging)

NOTE: The STATE DID NOT provide the "SERVICE" OF "Personal Care" / Personal Assistance Service (PAS) under the REGULAR STATE FUNDED PROGRAM/STATE PLAN. (A major component and reason why PA sought funding through the HCBS 1915c waiver)

This resulted in individuals who would otherwise receive personal care services under the STATE Program...to access the service of " personal care" /PAS services through the 1915c HCBS waivers.

The evaluation and report, having identified Access, Eligibility and SERVICE Delivery issues and similarities within the current 11 HCBS waivers ... DPW asked MEDSTAT to also evaluate the feasibility of REDUCING (in some way) the number of HCBS waivers into one (1) single 1915c HCBS waiver.

MEDSTAT RECOMMEDATIONS: GENERAL OVERVIEW

1- **MIS-ALIGMENT MANAGEMENT STRUCTURE**
The MedStat Report found that the HCBS waiver programs **WERE NOT** being managed as efficiently as they COULD/SHOULD have been. Specifically;
   - resources allocated were NOT being used in a manner that maximized their cost-efficiency in reducing the use of institutional services.
   - **Fragmented structural issues were too great to fix** and contributed to diffused accountability of financial incapabilities... for example Medstat found that OMAP retained ultimate responsibility for ALL 11 HCBS waivers but retained only minimal management oversight over (8) HCBS waiver programs administered
   - The Dept of Aging did not have any management or budgetary responsibilities over nursing facilities services or the Aging Waiver itself.
   - This fragmentation extended throughout management and financial information systems that were critical in/to tracking Utilization and costs. These reports "were usually unavailable to management authorities when needed or requested on a timely basis".. These citation was emphasized by the word **"REMARKABLE".**

2- In 2006 the THEN Governor realigned the management structure for long term living services, which comprised of (6) senior state officials: **The Sec. of DPW**, the Budget Sec, **the Policy Sec**, the Deputy Chief of Staff, **the Director of LTL council** and the Aging Secretary. **A new position: Executive Dir of Long term Living : was created.** The Executive Director of LTL would have RESPONSIBILITY of the OVERALL management for the coordination of Long Term Living policy and Operations throughout the commonwealth of PA. This position would report directly to the 6 positions: (Senior State Officials stated above).

3- The report concluded) that this new management structure made sense but it was to early in its creation to evaluate its impact but it was felt that its structure should address the many underlying structural problems that were evident as well as bring greater coordination, communication and efficiencies throughout the State.

4- **THIS POINT NEEDS TO BE MADE VERY CLEARLY AND LOUDLY....CONTRAY TO WHAT RUMORS ARE AND HAVE BEEN PUT OUT THERE BY THE STATE REGARDING THE SMOTHNESS OF OPERATIONS AS THEY RELATED (THEN) AND THE SERVICE DELIVERY MODELS OF 1915c HCBS WAIVER (S) (THEN) AND THE PROVISION OF THE VARIOUS WAIVER(S) "SERVICES" (THEN) ..... SHOULD NOT HAVE REMAINED VISIBLE REMINENTS TODAY.**

THIS REPORT THANKFULLY IS ONE OF ONLY A FEW DOCUMENTS THAT ARTICULATES THE TRUTH.... THE STATE (SINCE 2000) WAS VERY CLEARLY UNDER THE "WATCHFUL EYE" of THE FEDERAL GOVERNMENT/CMS for NON-COMPLIANCE IN MEETING/SATISFYING 1915c HCBS Waiver EXPECTATIONS/ASSURANCES AS APPROVED (BY THE FEDERAL GOVERNMENT via (CMS) REGARDING THE ADMISISTRATION AND PROVISION OF 1915C HCBS WAIVER PROGRAM(S) (ALL OF THEM).... IN A UNIFORM MANNER CONSISTANT WITH FEDERAL HCBS MANDATES, GUIDELINES, RULES AND REGULATIONS, ACROSS ALL GEOGRAPHIC REGIONS.

To the states credit if you can call it that, similar citations were also being echoed across ALL States at the time. States, in general, viewed 1915c HCBS waivers and their federal funding as new money sources that they (the State) could in some way divert and use for/in support of other "special Interest" service delivery programs. The federal government knew this ... hence the OLMSTEAD LETTERS (2000 – 2011) and finally with CMS Final RULE (2016).

5- **The report stated ... Evidenced with the reports findings.... <u>The State (Pennsylvania) was at risk of non-compliance with Medicaid laws and regulations. In general the state needed to strengthen its oversight role waiver program operations as well as its ability to monitor policy activities.</u>**

MEDSTAT REPORT: SPECIFICS:

1- **Develop UNIFORM ASSESSMENT Processes**
   At the time there was no uniform assessment instrument of assessing clinical eligibility for nursing and HCBS waiver services. Simply put this makes it difficult to make reliable assessments of whether waiver programs are being EFFECTIVE as they relate to Targeted Populations. **<u>This inability also restricts the assessment of EQUITABLE provision and distribute of waiver services and resources both in terms of addressing individual needs</u> and provider reimbursement.**
2- **<u>STREAMLINE the ELIGIBILITY PROCESS for "AT RISK" applicants... EXPAND COMMUNITY CHOICE to STATEWIDE.</u>**
3- **Prioritize Waiver Services**... target individuals already in institutions and those most at risk of institutionalization

4- DEVELOP RESIDENTIAL SERVICE COMPONENTS in HCBS waiver programs

5- **Provide increased continuity in Case Management Services**. PA WAIVERS DID NOT PAY FOR CASE MANAGEMENT SERVICES or SUPPORTS COORDINATION when the waiver participant experiences short term hospital or nursing facility stays. (SXC's) are responsible for ensuring cost effective service continuity after discharge and restart of HCBS services ... Yet they are not part of the Discharge process.... And these discharge planning items ARE BILLABLE under Medicaid.

6- **SEPARATE CASE MANAGEMENT SERVICES FROM DIRECT CARE SERVICE PROVISION.** This expectation/issue has always been directly cited in every 1915c HCBS waiver Application and Technical Guide version.

NOTE : IN 2012, Pennsylvania finally make it official in word and process to enforce regulation 52.28 Conflict Free Service Coordination. Code 55 Chapter 52: LONG-TERM LIVING HOME AND COMMUNITY-BASED SERVICES regulations were created in June 2011. And prior to that ALL guidance was promulgated through (THEN) DPW (NOW DHS) ... albeit lacking still needed clarity... Specifically regarding Participant Directed services. (SEE: Pennsylvania's Guide to Participant-Directed Services Department of Public Welfare Office of Developmental Programs September 2008. (Attached # 2).

7- **CONCOLIDATE HCBS WAIVERS**
This report recommended (THEN in 2006) that Pennsylvania should consolidate existing 1915c HCBS waivers into (1) one waiver. **Specifically: One (1) waiver for ALL persons under the age of 60 with physical disabilities.**

NOTE: In 2018 Pennsylvania officially transitioned into a NEWLY formatted waiver called.... CHC-Community Health Choices waiver. The State AMENDED the existing CommCare waiver :....(in essence renaming it to the: Community Health Choices waiver.... combing: the Aging, Independence and Attendant Care waiver(s) into one (1) single 1915c HCBS waiver.

ANOTHER Interesting point is that, (THEN DPW) requested that MEDSTAT consider evaluating the feasibility of the State applying for 1115 Independence Plus status as part of its evaluation of its HCBS waiver(s) and /or program.

Since 2002, the Independence Plus designation concept was created to be a standalone waiver that basically meant that there is one(1) HBCS waiver through which ONLY consumer directed service delivery models were offered. Over time with the recognition that many states (INCLUDING PENNSYLVANIA) already employs "Consumer Directed" service delivery models within their CMS approved 1915c HCBS waiver(s). Today Independence Plus status has evolved into a seal of approval more than a waiver designation.

That said, in 2006 CMS- through its updated "1915c HCBS Application and Technical Guide" mandated that with each waiver renewal or start of a new waiver : a STATE CAN/COULD ELECT TO APPLY FOR independence PLUS status or NOT. BUT THE LACK OF THIS STATUS DOES /DID NOT MEAN THAT THE STATE DOES NOT PROVIDE "CONSUMER DIRECTION" WITHIN ITS 1915c HCBS waiver program. It only

meant that the state version of "Consumer Direction" model(s) does not meet CMS Independence Plus criteria.

Part 2-

FULL AND EQUAL ACCESS DOES NOT MEAN "SEPARATE BUT EQUAL"

This is a good place to Segway into the exploring of EXACTLY WHAT IS the Federal and STATE requirements/DEFINITIONS of Consumer Direction as it relates to 1915c HCBS waiver services.

In the 60's, 70 and 80's there was a movement referred to as the DISABILITY RIGHTS MOVEMENT. This movement was not just to change public perception of the disabled community... it was to get FORMAL recognition and the individual empowerment of that recognition as a Civil Right.

Without recounting the history of this movement in depth.... Society as a whole was at a point both in general and politically.... Especially those who were in power.... And being touched by someone and or loved one who had a disability. Both political leaders and society in general were ultra sensitive to the recognition of the "UNEQUAL" treatment movement. .. as a result of Segregation and the Civil Rights movement. So much so that Congress and the Senate took action that addressed the issue through what is today referred to as ADA..... the Americans with Disabilities Act (1990).

At the time there were many situations, laws and legal cases that moved this movement down the LEGAL road. BUT! The passing of ADA-Americans with Disabilities Act..... in 1990 .... really cleared the way for FINAL RESOLUTION of this matter. **THIS WAS CLEARLY THE FIRST HISTORIC ACTION IN THE CHAIN OF EVENTS REGARDING THIS MOVEMENT**

The Americans with Disabilities Act (1990) is even more historical than the US Supreme Court decision of (1999) referred to as the "OLMSTEAD DECISION". As a result of the civil Rights movement, both Congress and the Senate, in their respective actions, re-visited the Civil Rights Act of 1964.

We all know that the Civil Rights Act made discrimination based on race, religion, sex, national origin and **other characteristics** illegal, **But with the passing of ADA, both Legislative chambers targeted the phrase "Other Characteristics"....** Both bodies , as a result of the historic case Brown v the Board of Education and other precedent cases, identified this phrase as being vague, and really wanted to jump into the "real purpose" of the Civil Rights Act which was first enacted in 1886.

It took some time because not all those in Congressional and Senatorial power had the same UNDERSTANDING.... Or said another way ... there was still significant societal and INSTITUTION BIAS.

But in the end, the Civil Rights Act of 1964 was historically codified and passed with the WORD "DISABILITY" codified into the Civil Rights Act .... thus adding the specific word "Disabilities" in the chain of classifiers designating and WARRANTING .... "Protected Class Status".

BUT the ADA added more fuel ... Specifically as it applies to the 14th Amendment of our countries Constitution;

SPECIFICALLY, the 14th Amendment: **Prohibits "discrimination" by ALL Public Entities** at the local level... school districts, municipalities, city or county **and at the STATE level.** It meant that ALL **Public entities MUST comply with "EQUAL PROTECTION CLAUSE" covering "FULL AND EQUAL ACCESS" to ALL programs and services offered by that entity.**

The "Equal Protections" Clause AS STATED IN THE ORIGINAL CIVIL RIGHTS ACT OF 1868 reads:

*"**nor shall any State** [...] **deny** to **any person** within its jurisdiction **the equal protection of the laws**".*

A primary motivation for this clause was to validate the equality provisions contained in the Civil Rights Act , which guaranteed that all citizens would have the guaranteed right to equal protection by law.

The significance of ADA and the Civil Rights Act was finally tested in 1999 with OLMSTEAD. Each previous court test although won (at the lower courts) by those claiming discrimination, were appealed and appealed again eventually ending up at the U.S . SUPREME COURT.

The second historic event was heard by the US SPREME COURT. Historically the ruling, referred to as **"the OLMSTEAD DECISION"....** put the attainment of disability rights on steroids.

It is unfortunate that in life that there will always be those who have the POWER, the MEANS to or try to deny/suppress the rights of others ... It is done every day! Although ADA was statutorily codified, individuals with disabilities still had to fight for the simple recognition of their "guaranteed protection of their Civil Rights" and against discrimination even before they were allowed to seek enforcement of legal remedies through the courts.

IMPORTANT NOTE: These two historical events were fundamental to the establishment of the Federally funded 1915c Home and Community Based (HCBS) waiver program.

But the real beauty of ADA and Olmstead and the Civil Rights Act was that it established the enforcement arm (via the DOJ-Dept. of Justice) to fight on behalf of those believing that they were discriminated against. It is here and the reason why I write this paper.

In the Olmstead Decision (Olmstead v. L.C. and E.W.) the court reviewed that the **"STATES OBLIGATION"** of the "INTEGRATION MANDATE" as cited in the ADA-Americans with Disabilities Act ALONG SIDE the BANNED acts of discrimination of the CIVIL RIGHTS ACT on the basis of mental or physical disability to mean **ABSOLUTE**.

In a nut shell (in OLMSTEAD) the plaintiffs sued the State of Georgia and the institutions where they were being housed claiming that they (the plaintiffs) because of their "disability" were forced to receive treatment and services in that facility. Further .... While these "services" could have otherwise been/be provided in a non-facility setting....

The court ruled under Title II : (of ADA) that mental illness is a form of disability: and therefore covered by the Civil Rights Act . Furthermore, that under ADA ....

"unjustified institutionalization/isolation of a person with disability is a form of discrimination because it perpetuates unwarranted assumptions that persons so isolated were incapable or unworthy of participating in community life"..... the court added, "Confinement in an institution severely diminishes the everyday life activities of individuals, including family elations, social contacts work options, economic independence, educational advancement and cultural enrichment".... Therefore NO person with a disability can be unjustly EXCLUDED from participating in or be denied the benefit of a service, program or activities of any public entity who could otherwise use and benefit from the those same services as if they DID NOT HAVE A DISABILITY".

It is the key phrase .... " .... use and benefit from the those **SAME SERVICES** as if they DID NOT HAVE A DISABILITY..." .

NOTE: *AS you will read ... **"VESTIGES OF DISCRIMINATION"** ... as cited in(Brown v the Board of Education) in essence calls out and addresses the perception of.... willfully intended or not ... any action(s), any policy(ies) or any law(s) of a State or public accommodation or service (regardless of how the provision of that service is worded) results in denying "FULL ACCES" S to the "SAME" service(s) afforded to everyone else..... **is a violation of the 14th amendment... is a violation of one's Civil Rights. Because that determining methodology or act disenfranchises, denies FULL ACCESS to a "SERVICE" (which is already defined as a service package afforded to every other individual) .... Because they (the individual) has already been determined eligible to receive those same services. Simply stated , there is no situation or event process or requirement in which an individual can be cohered to or choose to freely "GIVE UP" any part of their Constitutional Rights.***

With the passing of the ADA and the Olmstead Decision and the subsequent OLMSTEAD LETTERS it is clearly pointed out that the Civil Rights Act and the "establishment" of what is characterized as the "Protected Class" ... discrimination ... **and its discriminatory practices** applies to the other PROTECTED CLASSES / TARGET GROUPS IN THE SAME WAY.

NOTE: ***The US Supreme Court has been crystal clear in that ... it matters NOT the context "discrimination" is perpetrated... discrimination in any form or context.... IS a violation of one's Civil Right!***

Brown v the Board of Education consisted of a series of (3) US Supreme Court Rulings .... Each EVOLVED /ENHANCED the previous ruling.. showing a trend that the court DID NOT JUST APPLY the act of discrimination to situations of racial discrimination.... Or educational discrimination.... Rather **the practice of discrimination was viewed through the lens of the "absoluteness " of the Civil Rights Act....., IT DIRECTLY CLEARLY APPLIES TO ANY PUBLIC SERVICE .**

In Brown v The Board of Education) , the court historically cited and attacked the **Practice** of "discrimination" and found the practice of discrimination to be inherent in that which AFFECTED class(es)....

This applies to the manner in which that discriminatory practice no matter how (indirect, direct, obvious or subtle or covert, willfully intended or unintended) is UNEQUITABLY found in discovering that practice ,,,, as a discriminatory practice.

In Brown v Board of Education TRILOGY of cases

- **The US Supreme Court declared racial segregation in Public Schools as UNCONSTITUTIONAL**
- **The Court also declared that SEPARATE educational Facilities were inherently UNEQUAL and therefore were Unconstitutional. SEPARATE BUT EQUAL is UNCONSTITUTIONAL REGARDLESS OF THE MEANS OR PRACTICE EMPLOYED.**

In the BROWN case, it forced our US Supreme court to revisit and re-evaluate (as humans first than as US citizens) the courts acknowledgement of individual civil rights in the totality of the first few words of our nations constitution...

The first US Supreme Court case commonly referred to in the discussion of racial discrimination was PLESSY v FERGUSON **(1896)** ... in which the court declared "SEPARATE BUT EQUAL" / JIM CROW laws and Segregation **WERE** legal and NOT a violation of the 14th Amendment..

In this case the courts asserted that as long as the "accommodation" of that service was supplied.... Provided .... regardless of the manner in/by which that service was UNEQUALLY applied/distributed... it was legal and acceptable.

Jim Crow laws in essence meant , at the time, that literally ALL forms and types of accommodations PUBLIC or PRIVATE.... Schools, bathrooms, restaurants, drinking fountains , bus waiting areas, movie theaters, swimming pools.... You name it and there was in some manner or fashion a CONDITION ... Jim crow law.... Justifying the legal separation /use of white people from black and other non-white people in the use and access of/to that accommodation.

The highest court of this land upheld this constitutional interpretation of JIM CROW LAWS as the law of the land for some 58 years after Plessy. Although academic teaching commonly assert that these practices were pretty much concentrated in the "Southern States"..... The FACT was/is that albeit that the US Supreme Court is/was housed in a northern State..... the judges that served at the time (a life time tenure mind you) were predominantly from southern states and so it took some time to appoint a greater mixture of more enlightened justices to the bench.

It was not until Brown v Board of Education **(1954)** that the US Supreme Court's composition was such that this country made legal change possible. To put this in perspective 1954 was only 65 years ago... POWERFUL RIGHT!

The Brown case and decision forever documented in detail involved the combination of (4) FOUR other similar school segregation cases rolled into a single unified case. **Each based on variants of the HEART of discrimination....**

The Court decided all five cases together as one, which it called *Brown v. Board of Education*. The other cases were:[2]

- ***Brown v. Board of Education***
- *Bolling v. Sharp* (filed in Washington, D.C.)
- *Briggs v. Elliot* (filed in South Carolina)
- *Davis v. County School Board of Prince Edward County* (filed in Virginia)
- *Gebhart v. Belton* (filed in Delaware)

BROWN focused attention on the question of the constitutionality of segregation itself.

The (THEN) attorney Thurgood Marshall argued that the very fact that black students were separated from white students damaged the self-esteem, self-image, of the black students and made it plainfully clear that black students were "unworthy of being educated in the same classrooms as white students and that segregation reinforced notions of inequity associated with race prejudice and racism.

In the end Plessy was over turned by the US Supreme Court citing that segregation violated the 14th amendment.... GUARNTEE of "EQUAL Protection of the law".... Thus ...the doctrine... of "separate but equal" has no place in and is inherently UNEQUAL and rejected in any use of language .

The courts declaration applied to ALL ASPECTS OF LIFE.

In the summer of 1955 (four years later) the US Supreme Court issued its implementation ruling is what is referred to as **BROWN II ... ordered that schools undertake de-segregation with "ALL DELIBERATE SPEED" .**

BUT THERE WAS RESISTANCE .... What I categorize as "SELECTIVE INCOMPETENCE" or INSTITUTIONAL BIAS.

Which forced the court to address enforcement by individually addressing all areas related to : The Civil Rights Act (1886) and the 14th Amendment.

In June 11th 1963 JKF in his Report to the American People on Civil Rights... he asked the Legislature (Congress and Senate) to give ALL Americans the RIGHT to be served in facilities which are open to serve the public; hotels, theaters, retail stores, and similar establishments/accommodations as well as greater protection for the right to vote. INTERESTLY is the added fact that JFK's words emulated the Civil Rights Act of 1886, The voting Rights Act (1965) – 15th Amendment, The Housing Rights Act (1968), Amending Article 1 – Interstate commerce section 8

NOW it is important to understand how the passing of these acts/laws really motivated/motivate states to comply. Simply put, in our FEDERALIST construct of the United States of America, the only way the

Federal Government could entice STATE compliance is through "Power of the Purse" as it relates to and for what each state receives in federal funding : to fund..... their schools, roads, education systems and/or the provision of state and federal subsidized programs.

In essence, the federal government told each state that if you did not comply with federal law .... "It is your choice.... but be mindful that the federal government WILL NOT continue to fund any program, business and national guard or provide federal aide in emergency situations to that state in which non-compliance with the intent of federal law(s) is demonstrated'.

This has NEVER BEEN EFFECTED OR EXECUTED, BUT IN BROWN v THE BOARD OF EDUCATION the line was clearly drawn in the sand and the Federal Government was NOT going to give in.

In yet another in the linage of Brown v Board of Education : 1978 case,

At issue was that Topeka Schools were instituting a policy "Open Enrollment" to attend schools.

The Plaintiff argued that this policy, would continue to lead to segregation by white parents shifting their children to "preferred" schools , in essence to those schools private and/or public that would be out of the financial reach/means of low income minority and black families thus creating predominantly black and minority schools..... especially in those areas where the white families did not currently live.

The 10th circuit court did reopen the original Brown case but found against the plaintiff (Brown). However in 1989, the U.S. Supreme court overturned the 1975 ruling citing that there still remains "VESTIGASES OF SEGREGATION". And issued additional desegregation implementation rules. Which simply put that **FULL AND EQUAL ACCESS** as the barometer to/for "Equal Protections under the Law".

A side Note: *The Voting Rights Act 1965 –*

Prohibits racial discrimination in voting: Outlawing TESTS AND SIMILAR DEVICES AND PRACTICES that historically disenfranchised racial minorities. ***(This Law also applies to Discrimination)***

SECTION 5 *– Prohibits implementing any change affecting specific minority groups bilingual ballots and other voting material.... Striking down Section 4 (b) coverage Formula – which prohibits egregious (flagrant) voting discrimination practices.*

In other words the RIGHT to votes can NOT be "in some way" or "manner" DENIED.

I cites these cases and statutes as a matter of articulating the ABSOLUTENESS of the "EQUAL PROTECTION CLAUSE".

The last two clauses in the first section of the Constitution ..... in essence .... DISABLES a State form depriving not merely a citizen of the USA but any person whoever they may be of LIFE, LIBERTY or Property WITHOUT DUE PROCESS of law. Or denying him/her the EQUAL PROTECTIONS of the laws of the State. This ABOLISHES all legislation in ANY State or by any "State Actor" perpetuating the injustice

of subjecting a particular group of a caste (TARGET GROUP) to a code but not applying that same code "Equally" to another group of the same caste (TARGET GROUP) in the same manner for that same code or accommodation.

FURTHER THAT THERE IS NO CONDITION OR QUALIFYING PATHWAY AS ENUMERATED IN PLESSY THAT CAN JUSTIFY THE UNEQUAL PROVISION OF THAT SERVICE....

In the New York Law Journal – A Column titled : "Applying the Constitution to private actors" (April 28 2009) By Christopher Dunn

This article puts forth notable developments of the US Supreme Court during the 1960's that expanded the application of the Civil Rights Act to private actors through an expansion of the concept of "State Action". (Burton v Wilmington Parking Authority) ... which challenged the exclusion of blacks from a private restaurant.

In this case, A coffee Shop operated commercial space within a parking garage of a governmental agency in which the Parking Authority contracted and operated.

The precipitating issue of this case was that Burton (the Plaintiff) was refused service at the Coffee shop. Burton sued both the Coffee Shop as well as the Parking Authority on the grounds that his 14 amendment right to "equal protection clause" was violated.

The real issue of this case was whether or not the Coffee Shop was an "Actor of the State".

The court found that it (the Coffee Shop) was an Actor of the State. The court decided that because the Coffee Shop LEASED space in a Building that was built with FEDERAL DOLLARS (in whole or in part) was managed by and provided a State public accommodation/service (parking Authority. That the 14th amendment **WAS** applicable under federal law and jurisdiction. In short, the Court stated that the Coffee Shop (albeit a private enterprise) conducted its business through a lease agreement with the Parking Authority. Further that because the building was built with PUBLIC funds and the space leased is a physical part of the building. The Coffee shop had to comply with Federal Law.

I mention this case because the current MCO-Managed Care Organizations that are currently contracted with the State of Pennsylvania to MANAGE the provision of the 1915c HCBS waiver are (AS STATE ACTORS) making ill advised policy and or service provision decisions ... contrary to and in direct violation and compliance with ALL of the federal laws cited above.

As directly communicated to me by each of these MCO's , the provision of 1915c HCBS waiver (CHC waiver) and its SERVICES "ARE IN OUR OPINON " ..... A "product". As a product (the 1915c HCBS waiver and the "services" it provides) are just another product /service offered through us (the MCO's) in a line of other products and services that WE (the MCO's) have procured the rights to manage and administer. As such it is OUR (the MCO's) decision (within in their understanding of their authorities as communicated to them by OLTL-Office of Long Term Living) to decide how and by what manner it (a

SERVICE) is offered within their current mode of service operations. In this case the "SERVICE" of specific to Consumer Directed Services .... PERSONAL ASSISTACE SERVICES.

This in light of the obvious fact that every database every data entry portal regarding the location and selection of a provider, services delivered especially as they involve the SERVICE of PAS is rooted in HOME HEALTH CARE and NOT HOME CARE. (Please read Position Paper " HOME CARE IS NOT HOME HEALTH CARE". The MCO' are warned that in the area of Consumer /Participant Direction.

OLTL-Office of Long Term Living has only recently issued a guideline clarifying Consumer/Participant Directed Services.... **(as OLTL defines it)** in: OLTL BULLETIN 59-18-01 "Standardized Participant Information Packet" (January 2018).

What has be promulgated by OLTL is the reason of and for this paper. Because **ONLY Dept. of Human Services- DHS, (the LEAD Medicaid Agency of the State of Pennsylvania) SHOULD issue any document that represents a SUBSTANTIVE change to the intent as stated in the 1915c HCBS waiver... and ONLY then after securing the approval of CMS. SEE: CMS Technical Guide)**

PART 3

OFFICE OF LONG TERM LIVING

Participant Information Packet (Updated January 2018).

OLTL "QUALIFYING PATHWAY" FOR PARTICIPANT DIRECTION

Lets start by visiting: Pennsylvania's Attendant Care Act 1986.

NOTE: This act was the prerequisite accommodation of a state, (Pennsylvania), to align its STATE PLAN (in this case Pennsylvania's - Act 150 program) to and with 1915 HCBS waiver funding requirements (as set in its original 1915c HCBS waiver regulations) in order to apply for and granted 1915c HCBS waiver funding from the Federal Government, should the submitted application (1915c HCBS waiver proposal) meet Federal 1915c HCBS waiver requirements.

Also noted in the MEDSTATE Evaluation Report (mentioned above) , the State Plan at the time DID NOT AFFORD Attendant Care services in a person HOME and that Pennsylvania (THEN) was one of a few States at the time that were recognized for their pioneer efforts in the area of Home and Community Based Supports.

It reads as follows:

ATTENDANT CARE SERVICES ACT

Act of Dec. 10, 1986, P.L. 1477, No. 150 Cl. 67

AN ACT

To require the Department of Public Welfare **to provide home-based care as an alternative to nursing home or other institutional care.**

Compiler's Note: The Department of Public Welfare, referred to in this act, was redesignated as the Department of Human Services by Act 132 of 2014.

The General Assembly of the Commonwealth of Pennsylvania hereby enacts as follows:

Section 1. Short title.

This act shall be known and may be cited as the Attendant Care Services Act.

Section 2. Declaration of policy.

The General Assembly declares it is the policy of this Commonwealth that:

(1) The increased availability of attendant care services for adults will enable them to live in their own homes and communities.

(2) Priority recipients of attendant care services under this act shall be those mentally alert but severely physically disabled who are in the greatest risk of being in an institutional setting.

(3) Recipients of attendant care **have the right to make decisions about, direct the provision of and control their attendant care services. This includes, but is not limited to, hiring, training, managing, paying and firing of an attendant.**

(4) Attendant care services may be provided by county governments and county human service departments.

(5) Subject to available funds, attendant care programs should be developed to serve eligible individuals throughout this Commonwealth.

Section 3. Definitions.

The following words and phrases when used in this act shall have the meanings given to them in this section unless the context clearly indicates otherwise:

"Attendant care services."

(1) Those basic and ancillary services which enable an eligible individual to live in his home and community rather than in an institution and to carry out functions of daily living, self-care and mobility.

(2) Basic services shall include, but not be limited to:

(i) Getting in and out of a bed, wheelchair and/or motor vehicle.

(ii) Assistance with routine bodily functions, including, but not limited to:

(A) Health maintenance activities.

(B) Bathing and personal hygiene.

(C) Dressing and grooming.

(D) Feeding, including preparation and cleanup.

(3) If a person is assessed as needing one or more of the basic services, the following services may be provided if they are ancillary to the basic services:

(i) Homemaker-type services, including, but not limited to, shopping, laundry, cleaning and seasonal chores.

(ii) Companion-type services, including, but not limited to, transportation, letter writing, reading mail and escort.

(iii) Assistance with cognitive tasks, including, but not limited to, managing finances, planning activities and making decisions.

"Department." The Department of Public Welfare of the Commonwealth.

"Eligible individual." Any physically disabled/mentally alert person 18 through 59 years of age who meets all of the following requirements:

(1) Experiences any medically determinable physical impairment which can be expected to last for a continuous period of not less than 12 months.

(2) **Is capable of selecting, supervising and, if needed, firing an attendant.**

(3) **Is capable of managing his own financial and legal affairs.**

(4) Because of physical impairment, requires assistance to complete functions of daily living, self-care and mobility, including, but not limited to, those functions included in the definition of attendant care services.

"Personal care attendant." An individual other than a family member who provides attendant care services to eligible individuals.

"Secretary." The Secretary of Public Welfare of the Commonwealth.

Compiler's Note: The Department of Public Welfare, referred to in this section, was redesignated as the Department of Human Services by Act 132 of 2014.

The Secretary of Public Welfare, referred to in this section, was redesignated as the Secretary of Human Services by Act 132 of 2014.

Section 4. Program.

(a) **Establishment.--The department shall establish and develop under this act programs of attendant care services for eligible individuals.**

(b) Solicitation of proposals.--The department shall solicit proposals to provide attendant care services under this act. Providers shall submit proposals in the form and manner required by the department.

(c) Proposal selection criteria.--Proposals shall be selected based on service priorities developed by the department; however, priority shall be given to proposals that will serve the severely disabled and those at greatest risk of being institutionalized as defined by the department.

(d) Agreements with providers.--In order to provide attendant care services, the department may enter into agreements with providers. Each agreement shall include, at minimum, the number of clients to be served, the types of attendant care services to be provided, the cost of services,

the method of payment and the criteria to be used for evaluating the provision of services.

(e) Participation of eligible clients.--Providers, where appropriate, shall include eligible clients in the planning, startup, delivery and administration of attendant care services and training of personal care attendants.

(f) Consumer assessment reports.--Determination of eligibility and the need for attendant care services shall be supported by consumer assessment reports as required by the department.

(g) Weekly maximum hours of service.--Each attendant care provider agency's average hours of service per consumer must not exceed 40 hours per seven-day week.

(h) Waiting list.--The department and providers shall develop a waiting list, by service priority, for those eligible clients who cannot be served immediately.

Section 5. Funding.

(a) Use of funds.--Funds made available under this act shall be used only for the planning, designing, delivering and administering of attendant care services and training of personal care attendants.

(b) Federal and private funds.--Programs for attendant care services, under this act, shall use Federal funds, where possible. The department shall apply for and use, subject to specific appropriation by the General Assembly, all Federal funds which become available to carry out a program of attendant care services under this act. The department shall use any private funds which become available to carry out a program of attendant care services under this act.

(c) Program fee schedule.--The department shall develop, wherever practical, a sliding fee schedule for attendant care services for eligible clients.

(d) Disbursement of funds.--The department shall disburse funds in a manner that ensures, to the extent of available funds, equitable distribution of service among eligible clients with attendant care needs and among various regions of this Commonwealth.

(e) Availability of services.--Attendant care services shall be available only to the extent that they are funded through annual appropriation of State and Federal funds and program fees.

Section 6. Demonstration projects.

The department may initiate demonstration projects to test new ways of providing attendant care services, as well as conduct specific research into ways to best provide attendant care services in both urban and rural environments.

Section 7. Rules or regulations.

The department shall promulgate such rules or regulations as may be necessary for the effective administration of any programs of attendant care services under this act.

Section 8. Report.

Prior to June 30, 1988, the secretary shall submit a report to the legislative committees having jurisdiction over appropriations and the legislative committees having jurisdiction over health and welfare service. This report shall include at least the following information regarding attendant care services:

(1) A summary of the attendant care services provided under this act, including, but not limited to, a description of service models utilized, costs by service model, unit of service and per client, and client demographics.

(2) Recommendations regarding the direction of and funding priorities for attendant care services for fiscal years 1988-1989 and 1989-1990.

Section 9. Effective date.

This act shall take effect July 1, 1987.

NOTE: This Act makes NO mention of service delivery models "OTHER" means or methods of qualification ..... rather it uses the following words :

"Recipients of attendant care **have the right to make decisions about, direct the provision of and control their attendant care services ".**

This Act written purposefully using "absolute and all inclusive terms and words" to comply with the "EQUAL PROTECTIONS" and "FULL ACCESS" clauses of the 14th amendment.

As evidenced, in a **January 16 2018**, DHS/ Office of Long Term Living (OLTL) issued Bulletin # 59-18-01 titled "Standardized Participant Information Packet". **(Attached # 3)**

The Bulletins stated PURPOSE : **Is to ensure that ALL involved agencies are providing participants with uniform information. ALL CONSUMERS/PARTICIPANTS RECEIVE THIS PACKET.**

On page 3 of the PARTICIPANT INFORMATION PACKET under the heading: *YOUR RIGHTS AS A PARTICIPANT / CIVIL AND PERSONAL RIGHTS.* In part reads:

*"The **right** NOT to be discriminated against based on race, ethnicity, creed, national origin, religion, gender, gender identity, age, current or anticipated mental or physical disability, sexual orientation, genetic information, **or source of payment**";*

On page 4 under *"RIGHTS ABOUT GETTING SERVICE"* it states:

/

That the participant has *" The right to choose a provider (or at your (*the participants*) request, to have a provider chosen for you). You ARE NOT required – nor can you be forced-to to use a specific provider or to use one provider for all services".*

On page 5 under *"YOUR RESPONSIBILITIES as a PARTICIPANT" ... "To be active in making decisions and looking for and picking resources that best meet your needs".*

On page 7 under the heading PARTICIPANT CHOICE it states a question: *" DO I HAVE A CHOICE OF HOW I GET SERVICES AND WHERE I GET THEM FROM?"* It goes on to state:

"Yes, you HAVE THE RIGHT to choose how and where you will get services. You may choose to either receive services in your home, under the Living Independence For Elderly program (if eligible and it is available in your area) OR in a nursing facility.

If you decide to get services in your home, YOU will first choose a Service Coordination Entity who will provide you with a Service Coordinator. You will work with your Service Coordinator to make decisions about who will provide those services to you.... It goes on...

You may also choose to "Self Direct" your services by selecting the participant Directed Model. If you decide on Participant Directed Services, you or your designated representative are the "EMPLOYER" of your direct care workers and responsible for to hire, train and supervise your own workers.

NOTE: Under OLTL there are only (2) two service delivery models: 1- Fiscal Employer Agency F/EA and 2- Agency. However under CMS 1915c HCBS guidelines the "SERVICE DELIVERY MODELS" cited include 1; a Governmental Entity, 2- F/EA- Fiscal Employer Agent and 3- ANGENCY WITH CHOICE (AWC). PRIOR TO OLTL (2010) ALL "AGENCIES" OPERATED BOTH AS A FINANCIAL MANAGEMENT SERVICE (FMS) AND ALL "AGENCIES" OPERATED UNDER THE CLEARLY DEFINED OPERATIONAL PROTOCOLS OF A AGENCY WITH CHOICE.

On that same page , under *THE HEADING: CAN I CHOOSE ANY PROVIDER?* It reads:

You can choose from a list of agencies that are qualified to perform the "services" you have listed on your Individualized Service Plan. ***If you choose to self-Direct, you or your designated representative is are responsible for hiring, training and supervising the direct care worker(s) you have hired to provide your services.***

On page 18 to under the Heading: *"PARTICIPANT DIRECTED SERVICES":*

The question is asked: *What are Participant-Directed Services?* In response the State states:

Participant-Directed services let you take more control of your services and give you the power to manage your own workers. If you decide to self-direct, you are the employer of your direct care workers.

Office of Long Term Living Participant Directed Services are OFFERED in two ways, the EMPLOYER Authority and Budget Authority.

- *EMPLOYER AUTHITY, you are the employer of your direct care workers. You may hire a friend, neighbor or other trusted individual to be your worker. **AN AGENCY HELPS YOU TO ISSUE PAYCHECKS AND FILE TAXES. As the EMPLOYER, you are responsible for:***
  - *Recruiting and hiring worker(s)*
  - *Deciding your workers hourly rate, within a set range;*
  - *Training the worker(s)*
  - *Determining your workers job duties and schedule based on your service plan;*
  - *Supervise your worker(s) and approving his/her timesheets;*
  - *Reviewing your worker's performance; and*
  - *Firing your workers, when necessary*

NOTE: in the approved CHC HCBS waiver (2018) in APPENDIX E- Participant Direction of Services: E- 1-a: Description of Participant Direction. The State is asked:

In no more than two pages, provide an overview of the opportunities for participant direction in the waiver, including: (a) the nature of the opportunities afforded to participants; (b) how participants may take advantage of these opportunities; (c) the entities that support individuals who direct their services and the supports that they provide; and, (d) other relevant information about the waiver's approach to participant direction.

The State (Pennsylvania) RESPONDS:

Self-Directed Opportunities Available within the CHC Waiver:

"**All participants** have the option to make decisions about and self-direct their own waiver services as identified in Section E-1.g., below. Participants in the CHC Waiver may choose to hire and manage staff using Employer Authority **OR** manage an individual budget using Budget Authority. In addition, participants may choose a combination of service models to meet their individual needs. Participants are encouraged to self-direct their services to the highest degree possible. **During the actual provision of services, the participant is responsible for directing the activities of their support worker".**

Up to this point everything reads clear and understandable.

BUT wait! The participant Information Packet; (page 18), the document goes asks a question ..... " ***How are Participant-Directed Services Different from Agency Model Services?***

The State answered this question by stating: ***"The Agency model of service is available for participants THAT DO NOT WISH TO Self-Direct their services. In the Agency model , you would select a provider from an approved list of agencies to provide you services. The PROVIDER that you select recuits, hires and manages your direct care worker(s)".***

Let's stop here for a moment and digest what exactly OLTL is saying.

In light of what is clearly stated in Pennsylvania's APPROVED HCBS 1915c waiver Application: Specific citations taken directly from the source document (the approved 1915c HCBS waiver application) reads as follows:

On page # 2 *- Question # (3):* ***Nature of the Amendment: Component(s)*** *of the Approved Waiver Affected by the Amendment. This amendment affects the following component(s) of the approved waiver. Revisions to the affected subsection(s) of these component(s) are being submitted concurrently (check each that applies):* **NOTE: The State DID NOT MENTION APPENDIX E: Participant Direction at all.**

The waiver components that were cited include:

- Waiver Application Attachment #1: Transition : 1915b

NOTE: 1915b is used when transitioning to the use of Managed Care Organizations.

- Appendix B – Participant Access and Eligibility section ; APPENDIX B-6-a-i

NOTE: sets the minimum number of waiver services (one or more) that an individual must require in order to be determined to need waiver services is: 1 (one).

- Appendix D – Participant Centered Service Planning and Delivery section: APPENDIX D-1-b; D-2-b

NOTE: APPENDIX D-1-b: Establishes Entities and/or individuals that have responsibility for service plan development may provide other direct waiver services to the participant. And

NOTE: APPENDIX D-2-b : Establishes Entities and/or individuals that have responsibility to monitor service plan implementation and participant health and welfare may provide other direct waiver services to the participant.

- Appendix I – Financial Accountability section: APPENDIX I-3-g-ii

NOTE: APPENDIX I -3-g-ii: States : Yes! The waiver provides for the use of Organized Health Care Delivery System arrangements under the provisions of 42 CFR §447.10.

NO OTHER section(s), service definitions, and/or service delivery models and/or APPENDIX were amended from previously approved waivers.

ALSO In the approved CHC HCBS (2018) waiver application:

On page 67 : Appendix B: Participant Access and Eligibility B-7: Freedom of Choice: Appendix B: Participant Access and Eligibility B-7: Freedom of Choice : *Freedom of Choice. As provided in 42 CFR §441.302(d), when an individual is determined to be likely to require a level of care for this waiver, the individual or his or her legal representative is:*

i. informed of any feasible alternatives under the waiver; and

ii. given the choice of either institutional or home and community-based services.

(a) Procedures. PARTICIPANT FREEDOM OF CHOICE

The Commonwealth of Pennsylvania assures CMS that when a Nursing Facility (NF) or community resident applies for CHC waiver services and the participant is determined to likely require Nursing Facility level of care, the individual will be:

- **Informed by the IEB of all available home and community-based services,** including the Living Independence for the Elderly (LIFE) program for individuals aged 55 and over**; and,**
- **Given the choice of receiving Nursing Facility institutional services, waiver services, LIFE program services as appropriate, OR NO services.**

The State goes on....

"Participant Freedom of Choice of Care Alternatives"....

"All individuals who are determined to be eligible to receive community services in the waiver will be informed in writing, initially by the IEB of their right to choose between receiving community services in the waiver, LIFE, NF services, **OR choose not to receive services.** All eligible participants will execute his/her choice during the initial enrollment process and annually during the development of the person-centered service plan. Documentation is made in the participant's file that the form was completed; completed forms are maintained in the participant's file".

To me the reader, or any "OTHER" reader, of what the waiver is saying, these passages tell me that IF I (the consumer/participant) AM THE ELIGIBLE RECIPIENT OF THESE WAIVER SERVICES THAT I (AT THE INITIAL CONTACT) MUST EXECUTE MY DECISION TO EITHER RECEIVE 1915c HCBS WAIVER SERVICES OR RECEIVE **NO** SERVICES.

This paper asserts that page 18 of the Participant Information Packet, is MIS-LEADING and UNTRUE!!!

If OLTL is saying that although you (the participant) has already been approved as Eligible to receive 1915c HCB waiver services (have already made the decision to receive HCBS waiver services) .... That you (as a consumer/Participant) MUST AGAIN DECIDE to : *1) RECEIVIE HCBS waiver services in your own HOME OR 2) NOT receive HCBS waiver services.* ***IN ESSENCE CHOOSE TO EXERCISE YOUR RIGHT TO "PATICIPANT DIRECT YOUR HCBS WAIVER SERVICES OR NOT. BY MAKING A CHOICE BETWEEN A PROVIDER TYPE.... EITHER CHOOSE AN "AGENCY" OR THAT OF A "PARTICIPANT DIRECTION " MODEL.*** *.... And regardless of whether they choose to remain in a facility or in their own home... that IF they CHOOSE to receive their services through /under the "agency " model that they STILL WILL receive HCBS services ... BUT THOSE "SERVICES" (specifically the service of PAS)* ***WOULD NOT BE*** *PARTICIPANT DIRECTED.... IN OTHER WORDS, THE AGENCY WOULD OPERATE IN THE CONSUMERS OWN HOME AS IF IT WERE A FACILITY RENDERING FACILITY OR INSTITUTIONAL CARE.*

This is ABSOLUTELY FALSE. The moment you (as a potential participant) asks to receive 1915c HCBS waiver services, YOU have by your own actions are saying load and clear that you NO LONGER or DO NOT WANT TO RECEIVE FACILITY/ INSTITUTIONAL CARE. **(OLMSTEAD). And that by seeking HCBS waiver services, YOU accept ALL of the responsibilities of DIRECTING "SOME OR ALL" of your services.**

IF OLTL saying that if a participant wants to self-direct that THEY (the Consumer/Participant) MUST SELECT THE PARTICIPANT DIRECTION MODEL.

The Participant Information Packet (page 18) DOES NOT elaborate on what the PARTICIPANT-DIRECTED model or WHAT providers on the "LIST" of agencies" provide the Participant Direction Model.

Nor does the State/OLTL , in this Participant Information Packet, explain to a participant/consumer that their choice of providers is between "Agency" (of which there are many to choose from) or that of **the ONLY** Fiscal Employer Agent-(FEA).

As I have stated directly from the 1915c HCBS Application and Technical Guide its self. ALL HCBS waivers BY DESIGN OF THE APPLICATION entails that THE PARTCIPANT in some fashion SELF-DIRECTS "SOME OR ALL" of their services. Furthermore that if the waiver also includes (AND IT IS HIGHLY SUGGESTED BY CMS THAT STATE'S **AVOID** THE APPROACH OF **COMBINING** INDIVIDUALS WHO WANT TO SEF-DIRECT WITH THOSE INDIVIDUALS WHO DO NOT WANT TO SELF DIRECT IN THE SAME TARGET GROUP BECAUSE OF "SEPARATE BUT EQUAL" ASSERTIONS, SUCH AS STATED IN THE BEGINNING OF THIS PAPER).

INSTEAD the State SHOULD submit a separate 1915c HCBS waiver, if for the only reason(s) : the manner of which "SERVICES" are and must be provided is in direct conflict with the "SERVICE DEFINITIONS" of the approved waiver. **SEE : COMBINING WAIVER SECTION , SEE: APPENDIX E : EMPLOYER AUTHORITY SERVICE DEFINITION and SEE: Chapter 611: HOME CARE AGENCY and HOME CARE REGISTRIES governing licensure regulations.**

A long standing issue that has been reconciled in the courts regarding the rendering of a service in a person's private home is that determination that a person's private home or residence IS NOT A FACILITY and as such CAN NOT be regulated.... Even to the point that a person hired to render care DOES NOT HAVE THE AUTHORITY to simply walk in. This is called the "Castle Doctrine". Under this long established legal doctrine ... the person owning, renting, leasing that private home or residence... is the "KING" and that KING decides who enters and if allowed entrance... what that person will do... How long they will be there, etc...

Furthermore, OLTL DOES NOT SET THE LICENSING standards or requirements for a HOME CARE "AGENCY" and HOME CARE REGISTRY... in the provision of 1915c HCBS waiver Services (specifically the "SERVICE OF PERSONAL ASSISTANCE SERVICE- (PAS). In 2010, specific to the provision of the "SERVICE" of Personal Assistance Service-PAS, the authority to license a provider rests with the DEPT. OF HEALTH under Chapter 611- HOME CARE AGENCIES AND HOME CARE REGISTRIES which was specifically enacted in 2010 to license EVERY HOME CARE AGENCY providing the "SERVICE" of Personal Assistance Services-PAS (as defined) under 1915c HCBS Waiver(s).

§ 611.3. Affected home care agencies and home care registries.

(a) This chapter applies to home care agencies, home care registries and to entities that meet both definitions, profit or nonprofit, operated in this Commonwealth, as defined in this chapter. **This chapter does not apply to** a home health care agency, a durable medical equipment provider, a volunteer provider, or an organization or business entity designated under section 3504 of the Internal Revenue Code (26 U.S.C.A. § 3504) regarding acts to be performed by agents and either IRS revenue procedure 70-6 or IRS revenue procedure 80-4, that provides financial management services or supports coordination services, or both, to consumers of home and community-based services through Medicaid Waiver or other publicly funded programs.

In this regulation it defines both a HOME CARE AGENCY and a HOME CARE REGISTRY as follows:

§ 611.5. Definitions.

Home care agency—An organization that supplies, arranges or schedules employees to provide home care services, **as directed by the consumer or the consumer's representative,** in the consumer's place of residence or other independent living environment for which the organization receives a fee, consideration or compensation of any kind.

Home care registry—An organization or business entity or part of an organization or business entity that supplies, arranges or refers independent contractors to provide home care services, **as directed by the consumer or the consumer's representative,** in the consumer's place of residence or other independent living environment for which the registry receives a fee, consideration or compensation of any kind.

Independent living philosophy—A system of beliefs, concepts and attitudes that emphasize self-direction, control, peer support and community integration for individuals with disabilities.

Simply put, a Home Care Agency or Home Care Registry MUST OPERATE …. MUST PROVIDE "SERVICES" (provide the service of Persoanl assistance Service (PAS)) consistent with our licensure mandates. OR ELSE THEY (THE HOME CARE AGENCY/ HOME CARE REGISTRY) is in DIRECT VIOLATION OF ITS LICENSURE AND OF THE CONSUMERS CIVIL RIGHTS.

Furthermore in the 1915c CHC waiver itself, under APPENDIX E-1-a : Participant Direction of services : the State is asked:

Description of Participant Direction. *In no more than two pages, provide an overview of the opportunities for participant direction in the waiver, including: (a) the nature of the opportunities afforded to participants; (b) how participants may take advantage of these opportunities; (c) the entities that support individuals who direct their services and the supports that they provide; and, (d) other relevant information about the waiver's approach to participant direction. Self-Directed Opportunities Available within the CHC Waiver:*

THE STATE RESPONDED BY STATING:

All participants *have the option to make decisions about and self-direct their own waiver services as identified in Section E-1.g., below. Participants in the CHC Waiver may choose to hire and manage staff using Employer Authority or manage an individual budget using Budget Authority. In addition,* **participants may choose a combination of service models to meet their individual** ***needs****. Participants are encouraged to self-direct their services to the highest degree possible.* ***During the actual provision of services, the participant is responsible for directing the activities of their support worker****.*

Under Employer Authority, the participant serves as the common-law employer and is responsible for hiring, firing, training, supervising, and scheduling their support worker....

The State goes on to state....

How Participants May Take Advantage of Self-Directed Opportunities: *Participants may choose to self-direct "**certain**" services during the development of the person-centered service plan (PCSP), at reassessment, or at any time.*

There are two (2) AMBIGUOUS statements and terms used in the above stated response of PA/OLTL, they are:

1) **In addition participants may choose a combination of service models to meet their individual needs**

and

2) *Participants may choose to self-direct "**certain**" services during the development of the person-centered service plan (PCSP), at reassessment, or at any time.*

In addressing # 1 above: There are according to OLTL only 2 (two) Service delivery models publicly expressed as available for a participant to choose from regarding the manner in which they want their services delivered . These service delivery "MODELS" are : 1- Fiscal Employer Agent and 2- AGENCY.

NOTE: As stated in the CMS 1915c Application and Technical Guide: EACH of the Service Delivery models MUST BE what is referred to as FMS-Financial Management Services because 1- the Federal gov't prohibits the distribution of funds directly to a participant so that they can pay their workers and 2- to lessen the employer burden of the participants so that they can focus on living their lives.

Although CMS is clear in that ALL service delivery models MUST operate in the capacity of FMS in the provision of HCBS services, CMS was even more clear in that the service delivery models used by a state: MUST BE either be a Governmental /FEA- Fiscal Employer Agent **OR** a contracted FEA-Fiscal Employer Agent **AND/OR** a Agency With Choice (AWC).... THE STATE could choose the models that best fit the States operations but PARTICIPANT CHOICE MUST be available.

NOTE: In 2011, the Office of Long Term Living was " **suddenly** " ... (without any reason or formal public comment).... restructured and separated from the (THEN) Dept. of Public Welfare and placed under the DEPT. of Aging. There were NO regulatory (NO REGULATION AT ALL WERE PUBLISHED FOR NEARLY TWO YEARS BY OLTL) changes regarding the manner in which HCBS services were delivered. **PRIOR TO 2011 ALL PROVIDERS OPERATED AS AND DELIVERED HCBS SERVICES AS AWC –AGENCY WITH CHOICE PROVIDERS AND THERE WAS NO FISCAL EMPLOYER AGENT PROVIDERS.**

One of the first public statements made by OLTL (2013) was that OLTL WILL NO LONGER BE USING THE Agency With Choice-(AWC) MODEL. That OLTL will only use two (2) models: 1) Fiscal Employer Agent (F/EA) model and "AGENCY" model (No Service Definition was given). There was also no reason given as to why!

That said, IN ORDER FOR A "AGENCY" PROVIDER TO PROVIDE THE "SERVICE" OF PERSONAL ASSTANCE SERVICE (PAS), they (the AGENCY Provider) had to be licensed under the **newly enacted** Dept. of Health regulations : Chapter 611 as a HOME CARE AGENCY and HOME CARE REGISTRY... **NOTE: THE ONLY REASON FOR THE ENACTMENT OF THIS LICENSURE PATHWAY OR ITS REGULATION(s) WAS TO ADDRESS THE PROVISION OF THE SERVICE OF ; Personal Assistance Service- PAS.**

Which as stated above, in the SERVICE DEFINITIONS of this regulation states **A LICENSED HOME CARE AGENCY HOME CARE REGISTRY PROVIDER** IN THE PROVISION OF THE "SERVICE" OF PAS.... That "SERVICE" **MUST BE** provided ..... **"AS DIRECTED BY THE CONSUMER" .**

With regards to... "use a "COMBINATION" of models to meet their individual needs",... although worded as it has been since 2011, it is a complete MYSTERY to this author as to how "using in combination" can be achieved. Given that both service delivery models (FEA and or Agencies) have been defined in regulation regarding their respective purpose, operation and function... BOTH are in essence THE SAME.

For a participant to use these two types of service delivery models in "combination" has always been a question put forth to OLTL (WITHOUT A RESPONSE) as to how exactly that would work, especially as it relates to the provision of the "SERVICE" : PAS- Personal Assistance Services.

If the State/OLTL is stating that the ONLY service delivery model that can OFFER the right of the consumer/participant to self-direct is ONLY through the F/EA model which coincidentally is also the ONLY entity contracted with OLTL/State, there are several problems:

1- The consumer/participant has NO CHOICE BETWEEN PROVIDERS/TYPES
2- THE State/OLTL is in essence undermining the ENTIRE PURPOSE OF 1915c HCBS waiver main directive ... giving the consumer/participant control over "SOME OR ALL" of their services. In essence **changing "Some or All" to really mean "ALL or None".**

There are many more areas of which... should this be the States/OLTL's view .... That the state has PURPOSFULLY AVOIDED in its clear explanation of HOW EXACTLY PARTICIPANT DIRECTION is OFFERED TO OR ENSURED TO EVERY INDIVIDUAL DETERMINED ELIGIBLE AS PART OF THE DEFINED "TARGET GROUP" OF INDIVIDUAL CONSUMERS/ PARTICIPANTS COVERED UNDER THIS WAIVER.

THE STATE FAILED TO EXPLAIN TO CMS WHAT EXACTLY ARE THE "ALTERNATIVE" SERVICE DELIVERY MECANISMS/models AVAILABLE TO THOSE WHO DO NOT WISH TO SELF DIRECT.

EVEN THOUGH IN THE PROVISION OF HCBS WAIVERS THE STATES CLEARLY STATES THAT " DURING THE ACTUAL PROVISION OF SERVICES, THE PARTICIPANT IS RESPONSIBLE FOR THE SUPERVISION AND DIRECTION OF THEIR SELECTED WORKERS".

Now what exactly are those "CERTAIN" services that a participant can Self-Direct? For the purposes of this paper the "service" is that of Personal Assistance Services (PAS). Which as defined in Chapter 611.. IS the provision of the Service of PAS.... "**as directed by the consumer**".

In the only other regulation AN Agency provider must comply with : Chapter 52- **LONG-TERM LIVING HOME AND COMMUNITY-BASED SERVICES**; This Regulation defines personal assistance services and associated terms as follows:

Provider—A Department-enrolled entity which provides a "service".

Personal assistance services—"Service" aimed at assisting the participant to complete ADLs and IADLs that would be performed independently if the participant did not have a disability.

ADL—*Activities of daily living*—The term includes eating, drinking, ambulating, transferring in and out of a bed or chair, toileting, bladder and bowel management, personal hygiene, self-administering medication and proper turning and positioning in a bed or chair.

IADL—Instrumental activities of daily living—The term includes the following activities when done on behalf of a participant:

(i) Laundry.

(ii) Shopping.

(iii) Securing and using transportation.

(iv) Using a telephone.

(v) Making and keeping appointments.

(vi) Caring for personal possessions.

(vii) Writing correspondence.

(viii) Using a prosthetic device.

(ix) Housekeeping.

In chapter 611 - **HOME CARE AGENCIES AND HOME CARE REGISTRIES,** Personal Assistance Services and associated terms are defined as follows:

Consumer—An individual to whom services are provided.

Consumer control—Control and direction by the consumer in identifying, exercising choice of, and managing home care services in accordance with the consumer's needs and personal preferences.

Direct care worker—The individual employed by a home care agency or referred by a home care registry to provide home care services to a consumer.

Financial management services—One or more of the following services:

(i) Managing payroll including Federal, State and local employment taxes for direct care workers recruited and retained by the consumer.

(ii) Processing the payment of workers' compensation, health and other insurance benefits for the direct care worker.

(iii) Assisting consumers in calculating and managing individual budgets for Medicaid Waiver and other publicly funded home and community based services.

(iv) Monitoring the consumer's spending of public funds and any underage or overage in accordance with the consumer's approved budget.

(v) Collecting, processing and maintaining time sheets for direct care workers.

(vi) Providing training to consumers related to employer-related tasks (for example, recruiting, hiring, training, managing and discharging direct care workers and managing payroll and bill paying).

Personal care—The term includes, but is not limited to, assistance with self-administered medications, feeding, oral, skin and mouth care, shaving, assistance with ambulation, bathing, hair care and grooming, dressing, toileting and transfer activities.

Specialized care—**<u>Nonskilled services</u> unique to the consumer's care needs that facilitate the consumer's health, safety and welfare, and ability to live independently.**

In the CHC-Community Health Choices waiver (2018) as it pertains to Participant Direction: it reads as follows:

<u>NOTE:</u> The reader is strongly encouraged to read the Position Paper titled "HOME v HOME HEALTH CARE" because in the 1915c HCBS waiver (the CHC Community Health Choices waiver) in APPENDIX C: Service Specifications as well as in the Chapter 611 regulations defines the "SERVICE" of PAS as assisting the individual/participant in the completion of their Activities of Daily Living (ADL's and Instrumental Activities of Daily Living (IADL's)... (NON MEDICAL SERVICES) .... CAN ONLY BE PROVIDED BY A HOME CARE AGENCY OR A PROPERLY LICENSED "INDIVIDUAL" .

In Appendix E: Participant Direction of Services: E-1-b: Participant Direction Opportunities. THE STATE IS ASKED DIRECTLY- *Specify the participant direction opportunities that are available in the waiver.* ***<u>(Select one:)</u>***

___ **Participant: Employer Authority.** *As specified in Appendix E-2, Item a, the participant (or the participant's representative) has decision-making authority over workers who provide waiver services. The participant may function as the common law employer or the co-employer of workers. Supports and protections are available for participants who exercise this authority.*

OR

____ **Participant: Budget Authority**. *As specified in Appendix E-2, Item b, the participant (or the participant's representative) has decision-making authority over a budget for waiver services. Supports and protections are available for participants who have authority over a budget.*

OR

__X_ ***Both Authorities.*** The waiver provides for both participant direction opportunities as specified in Appendix E-2. Supports and protections are available for participants who exercise these authorities.

THE STATE OF PENNSYLVANIA CHOOSE "BOTH" AUTHORITIES. AGAIN THE WAIVER AS APPROVED MUST AFFORD "FULL AND EQUAL" ACCESS TO ALL "SERVICES" AS DEFINED TO ALL PARTICIPANTS APPROVED (TARGET GROUP) TO RECEIVE THOSE SERVICES.

Appendix E: Participant Direction of Services: (d)- **Election of Participant Direction.** *Election of participant direction is subject to the following policy **(select one)**:* The State/OLTL responded by selecting:

"The waiver is designed to afford every participant (or the participant's representative) the opportunity to elect to direct waiver services. Alternate service delivery methods are available for participants who decide not to direct their services.

Note: The question MUST BE asked at this point... What are the "alternative" service delivery methods available to the participant?

Appendix E: Participant Direction of Services: (g). Participant-Directed Services. *Specify the participant direction opportunity (or opportunities) available for each waiver service that is specified as participant-directed in Appendix C-1/C-3.* The State/OLTL responded by listing all "SERVICES" as well as defined each in APPENDIX C : SERVICE SPECIFICATIONS ARE PARTICIPANT DIRECTED.

Waiver Service	Employer Authority	Budget Authority
Participant-Directed Community Support		
Participant-Directed Goods and Services		
Respite		
Personal Assistance Services (PAS)		

Furthermore, on page 16 of the Application for 1915c Home and Community-Based Waiver [version 3.5 , Includes CHANGES IMPLEMENTED through November 2014], under the heading APPENDIX E: Participant Direction of Services it reads...

"This Appendix permits a stat to specify the opportunities afforded to waiver participants to direct and manage their waiver services. This appendix is completed ONLY when the waiver offers ONE or BOTH of the participant direction opportunities contained in the Appendix. The NEW application enables a state to offer participant direction in a waiver in which other service delivery models also are used OR , alternatively, provide that participant direction is the principle service delivery method that is used in the waiver".

In January of 2014 CMS – Centers for Medicare & Medicaid Services issued a NEW RULE which moved away from defining home and community based settings by " what they are not" and towards defining them by the nature and quality of participants experiences AS DEFINED within the philosophy of : SELF DIRECTION or CONSUMER DIRECTION.... Among the (5) major KEYS are:

Integrate in and support FULL ACCESS of individuals receiving HCBS... in opportunities to...

- CONTROL PERSONAL RESOURCES,.. to the same degree of access as individuals NOT receiving HCBS services.
- Allows the individual to SELECT from "setting options" as identified in the HCBS waiver and the individuals service plan
- Optimize, but does NOT regiment individual initiative, autonomy and independence in making life choices, including but not limited to DAILY ACTIVITIES and physical movement... and with whom it interact.
- **FACITATES INDIVIDUAL CHOICE REGARDING "SERVICES" AND SUPPORTS AND WHOM PROVIDES THEM.**

CONCLUSION:

As a matter of reference, HOME HEALTH CARE AGENCIES are also LICENSED UNDER DEPT. of HEALTH BUT UNDER CHAPTER 601, which covers the provision of "medically necessary" health care services.... The Home HEALTH Care agency CAN NOT provide the" SERVICE" of PAS... because THEY (Home HEALTH Care agency) IS NOT Credentialed as a HOME CARE AGENCY.

Other than the issues discussed and clarified above, THIS PAPER ASSERTS THAT: the participants ability to SELF-DIRECT is a given under the law..... **REGARDLESS OF THE SERVICE DELIVERY MODEL THEY SELECT. PERIOD!!!**

The CMS 1915c HCBS waiver Application and Technical Guide defines "PARTICIPANT DIRECTION" as affording each participant/consumer the ability ***to control "SOME OR ALL" of their HCBS service.***

The CMS 1915c HCBS waiver Application and Technical Guide is very clear that the waiver can EITHER AFFORD "PARTICIPANT DIRECTION" Opportunities OR NOT. The guide goes on to caution the STATE (in this case Pennsylvania) that a "SEPARATE " waiver SHOULD BE written to address those individuals who DO NOT want to Direct **"SOME OR ALL"** OF their HCBS waiver services.

The way and manner in which the State (Pennsylvania)/OLTL craftfully uses selective words and phrases .... Mutates, misguides and blurs the understanding and meaning of what should be straight forward.

It was not the intent of this paper to state whether this was done intentionally or not, or done so to simply justify or validate, or appease "INTITUTIONAL BIASES" of administrators , special interest and lobby groups or grant financial preference, but it was written to point out the possibility.

In Pennsylvania's 1915c HCBS waiver (albeit stated clearly for all to read and have a common understanding in the States/OLTL's General responses) the State/OLTL uses SELECTIVE wording and/or phrases that **SUBSTANTIVELY** CHANGES CMS definition(s) of a Participant' s ability to control "SOME OR ALL" of their services to mean a..... "ALL OR NONE" proposition.

As stated above the State/OLTL introduces these **SUBSTANTIVE** changes not in the general descriptive responses requested by CMS that give an overview and assurance of PARTICIPANT DIRECTION TO ALL. BUT rather in subtle word definition changes . For example: "SOME OR ALL" is the CMS phrase.... But the Pennsylvania uses just the word "SOME". The state also uses crafty operational opportunities i: like when it states "each consumer decides whether or not to self-direct by choosing a particular model over "that" model . Or in those instances where the State RE-DEFINES terms and phrases that are hard coded in the 19115c HCBS waiver Application evaluation criteria. Here is an examples:

In Appendix B: Participant Access and Eligibility B-7: **Freedom of Choice** The State in its approved application States:

Participant Freedom of Choice of Care Alternatives

All individuals who are determined to be eligible to receive community services in the waiver will be informed in writing, **initially by the IEB of their right to choose between receiving community services in the waiver, LIFE, NF services, OR choose NOT to receive services.**

If the individual ELECTS to receive HCBS waiver services : **All eligible participants will execute his/her choice during the initial enrollment process and annually during the development of the person-centered service plan.** Documentation is made in the participant's file indicating that the form was completed; completed forms are maintained in the participant's file. **NO ONE SEES THIS FORM.**

Participant Freedom of Choice of Providers. **The IEB is responsible for ensuring that all individuals who are determined eligible for waiver services are given a choice of CHC-MCOs**, and electronically documenting the participant's choice of CHC-MCO. After the participant selects a CHC-MCO, the IEB will process the enrollment and refer the participant to the selected managed care plan for services.

NOTE: If the individual consumer /recipient is receiving 1915c HCBS waiver services... they have acknowledged their ACCEPTANCE of their responsibility to direct "SOME OR ALL" of their services.

I offer the following STATE /OLTL copy of: CONSUMER CHOICE DOCUMENTATION THAT IS SIGNED BY EACH CONSUMER AS THEY INITIALLY MEET THEIR SELECTED SUPPORTS COORDINATION ENTIITY AND SUPPORTS COORDINATOR.

http://www.dhs.pa.gov/cs/groups/webcontent/documents/bulletin_admin/c_223105.pdf

As you can see , in the first page " SERVICE PROVIDER CHOICE FORM" it clearly states....

" Before you choose who will be providing your home and community –based services please be advised of the following:"....

1. **You may decide who will provide the services listed in your Individual Service Plan as long as they are an enrolled provider and are qualified to provide those services.**

2. **You may** talk to or **interview providers before making your choice of providers.** This can be a long process and may result in a delay of services.

3. You will not be forced to choose a particular provider.

4. You can decide on a different provider for each service.

5. You may choose more than one service provider to provide a service.

6. **You can self-direct "certain" services depending on your waiver.**

NOTE: It does not Mention SERVICE DELIVERY MODEL... IT STATES ... DEPENDING ON THE WAIVER. Also, the "SERVICE" OF Personal Assistant Service (PAS) as defined in APPENDIX C: Service Specifications reads CLEARLY: The "SERVICE" of Personal Assistant Services (PAS) CAN ONLY BE PROVIDED BY EITHER (1)- A PROPERLY LICENSED / CREDENTIALED HOME CARE AGENCY or a properly LICENSED /CREDENTIALED "INDIVIDUAL".

7. You can change your mind about who provides your services, including Service Coordination, at any time by telling your current Service Coordinator.

8. If there are issues you have been unable to resolve or it would be difficult discussing them with your Service Coordinator, you may call the OLTL Participant Helpline at 1-800-757-5042. There is no charge for calling this number.

In the waiver, the Supports Coordinator - SC has been entrusted with the responsibility to "competently" explain the "waiver" and ALL OF THE "SERVICES" it offers. It is also at this point where the SC must "competently" explain SELF-DIRECTION and how they (the Participant) can choose to self-direct or not (according to the state).

NOTE: If the waiver was approved, it was done so because CMS determined that it was in compliance with 1915c HCBS waiver evaluation criteria. Specifically that THE WAIVER AFFORDS **ALL** TARGET GROUP PARTICIPANTS "EQUAL ACCESS TO **ALL** OF THE SAME "SERVICES" (AS DEFINED IN THE WAIVER). Simply stated, the "SERVICE" of Personal Assistance Services (PAS) is PARTICIPANT DIRECTED **(AS DEFINED IN THE WAIVER) regardless of the SERVICE DELIVERY MODEL.**

NO WHERE IN THE STATE WAIVER APPLICATION (SPECIFICALLY IN THE BREIF DESCRIPTION OF THE WAIVER) WAS IT EVER MENTIONED OR REFERRED TO .... THAT THE STATE INTENDED TO ALSO COMBINE AND RE-DEFINE THE TARGET GROUP IN ANY WAY.... TO COMBINE **THOSE PARTICIPANTS**