

No Wrong Door Planning Group  
Meeting Transcripts (unedited)  
April 24, 2015



**Opening Comments: What Makes You Nervous?**

- Our work will be meaningless
- The system won't dovetail with what exists
- It will increase consumer confusion
- Overall distrust/concern about respect for civil rights
- Access for those with cognitive disabilities
- Moving the system to cover the lifespan
- Losing what works
- Worry whether it will really work for rural areas
- That staff training will be lacking
- That we won't be able to pay a living wage, leading to turnover
- Slanted towards institution-based services
- People falling through the cracks
- What will my agency look like?
- Duplication (of data, of documentation, etc.)
- Finger pointing
- Insufficient resources (esp. money)
- Will members of the GLBT – and other groups – really be welcomed?
- Statutory changes needed/timing/sequencing
- Federal funding ending
- Coordinating with other initiatives
- Resistance to change, culture change, going against existing incentives
- “Flavor of the month” attitude
- Resistance to consumer empowerment
- Concern about the power of CCBs/BHOs

## Implications of Work to Date

- We need some high financial benefits for staff; also more support (emotional)
- Professional liability insurance
- Highly centralized – tailored/customized – figure it out on your own continuum
- Need to be able to customize for the realities on the ground/what people in a certain area need that might be different
- Support to meet the standards
- Quality standard might have to vary? If you can show the data to show that it doesn't apply to your community
- State should be knocking on the door of the existing entities that have the 75-80% of competency that will be needed. Otherwise you're going to have the same entities submitting proposals that may not be the best model.
- State taking the initiative to really ID and vet
- And how many NWD certifications will there be to serve the state
- Aging vs. disability – a cultural thing; have seen some coming together; need to make sure people can retain their own cultural identity and also get the NWD services; services (disability) and natural supports (aging)
- Coveting: “I know what's best for my people” – there are certain parts of the system that need to be blown up
- Make it clear that this isn't blame – it is change because it will make things easier/serve more people
- Exploitation and neglect
- The experiences of the consumers are different – everyone gets old (hopefully); people with disabilities may feel blamed
- Get rid of the stuff that people don't want
- Carefully consider centralization vs. de-centralization – the state and 64 counties; that organizational structure and whether or not there's leverage with the counties – you could do a centralized system and the counties could do the opposite
- Look at the business processes that might be relevant (franchise, etc.)
- There are service dollars in both aging and disability funding streams
- There's expectations around private pay for some of our agencies
- If we can tap into the private pay market – that might be where the subsidy is for the work we want to do on the public side
- Insurance companies?
- We had a contract with employers to do care planning

- If we can set up a system that is as qualified as we are talking about – then it might be a place those private payors, employers, etc. could rely on
- The absenteeism rates connected to caregiving
- What if some of us told us what we have done to leverage private pay?
- You braid funding
- You don't want the incentive to push people to public dollars
- People in the middle class pay for their insurance, and as those rates go up, we have less available income to take care of living expenses. The people in the middle are caring for people in their families and paying higher insurance premiums
- The whole concept of private and public pay – I don't really know where you draw the line about what someone is entitled to. A lot of people haven't participated in something that they could have

### **Consumer Target Markets**

*In what ways might someone relate to getting connected to LTSS?*

- Means to independence
- Getting ongoing MH meds or help
- Caring for mom and dad
- Getting support because I don't have family
- Knowing how to find resources for when I need them
- I feel validated – understanding that I'm not alone
- I live in a less restricted environment
- Finding a safe place to live
- Not depending on friend and family/ not be a burden
- It's not for me
- Can let me live my life where I want – have choice
- This is where I get all my information in one place – relief
- I can get a job because I don't have to take care of mom
- I can get a job because I get the LTSS I need
- My patient will get what they need (healthcare provider)
- There's not going to a readmission (hospital)
- It will keep me out of the hospital/nursing facility
- I can stay in my home
- We can get matching dollars
- If my family member faces a barrier- we can get an answer
- I don't have to do/be everything for everyone

## Market Segment Profiles

Caregiver Segments	Profile
Older adults (children)	<ul style="list-style-type: none"> <li>• Expect the consumer to need care over the rest of the lifespan</li> <li>• Grief and loss (parts of their life; changes/deterioration)</li> <li>• The parent/child dynamic/family dynamics can get in the way of using/accessing services/ changing roles</li> <li>• The financial piece/ economic stressors</li> <li>• Prevention – I want avoid a crisis down the line</li> <li>• Isolation</li> <li>• I am operating outside my expertise – am I doing the right things?</li> <li>• Is this caregiver doing a good job? Anxiety</li> <li>• Injuries in the course of caregiving</li> <li>• Repairing the relationships – getting back to being a mother, daughter, etc. vs. a caregiver</li> <li>• Cumulative impacts of stress (financial, emotional, physical, etc.)</li> <li>• Being able to give care and still being able to do self-care</li> <li>• How do I get up to speed on all these systems?</li> <li>• Unforeseen consequences of my actions/ decisions</li> <li>• Overwhelm, uncertainty, anxiety, concern for self and for consumer</li> <li>• Disconnect between what they see is important and what the consumer things is important/ learning to respect that</li> </ul>
Older adults (peers)	<ul style="list-style-type: none"> <li>• Expect the consumer to need care over the rest of the lifespan</li> <li>• Grief and loss (parts of their life; changes/deterioration)</li> <li>• Caregiver loss of ability/capacity – if I die what happens?</li> <li>• The parent/child dynamic/family dynamics can get in the way of using/accessing services/ changing roles</li> <li>• The financial piece/ economic stressors</li> <li>• Prevention – I want avoid a crisis down the line</li> <li>• Isolation</li> <li>• I am operating outside my expertise – am I doing the right things?</li> <li>• Is this caregiver doing a good job? Anxiety</li> <li>• Injuries (physical) in the course of caregiving</li> <li>• Repairing the relationships – getting back to being a mother, daughter, whatever</li> <li>• Cumulative impacts of stress (financial, emotional, physical, etc.)</li> <li>• Being able to give care and still being able to do self-care/ no time for self-care</li> <li>• How do I get up to speed on all these systems? Unforeseen</li> </ul>

	<p>consequences</p> <ul style="list-style-type: none"> <li>• Overwhelm, uncertainty, anxiety, concern for self and for consumer</li> <li>• Disconnect between what they see is important and what the consumer things is important/ learning to respect that</li> </ul>
Person w/ disability (parent of child)	<ul style="list-style-type: none"> <li>• This is where I get all my information in one place – relief</li> <li>• I can get a job because I don't have to take care of family member</li> <li>• If my family member faces a barrier- we can get an answer</li> <li>• The effort I've been putting forth – I might be able to get paid (relief)</li> <li>• Relief re: economic stressors</li> <li>• Don't want to get too stressed out – need a break/respice</li> <li>• “Succession planning” – how am I going to keep my house? Etc.</li> <li>• Grief/loss/ my child may pre-decease me</li> <li>• Horrendous amount of guilt – over their pain, situation, not helping them enough</li> <li>• There is a community of caregivers</li> <li>• Respecting the right to risk</li> <li>• Fraught with fear – making a decision about physical need – if I do the wrong thing what are the consequences</li> <li>• It's more about increasing independence (recovery trajectory)</li> <li>• I want to have a life like everyone around me</li> <li>• Being asked to do more medical caregiving</li> <li>• When you have someone with a MH diagnosis – fear of the police, of the ER, etc.</li> <li>• Providing education, support, empowerment</li> <li>• Needing resources to be the parent their child needs</li> <li>• Knowing who to listen to – the doctor says this, the other person says....</li> <li>• Giving up expectation/ grief/ myths</li> <li>• Being told that things are possible – the choices are the choices I want</li> <li>• Tension between liability/payment</li> </ul>
Person w/ disability (parent of adult child)	<ul style="list-style-type: none"> <li>• This is where I get all my information in one place – relief</li> <li>• I can get a job because I don't have to take care of family member</li> <li>• If my family member faces a barrier- we can get an answer</li> <li>• The effort I've been putting forth – I might be able to get paid (relief)</li> <li>• Relief re: economic stressors</li> <li>• Don't want to get too stressed out – need a break/respice</li> </ul>

	<ul style="list-style-type: none"> <li>• “Succession planning” – how am I going to keep my house? Etc.</li> <li>• Grief/loss/ my child may pre-decease me</li> <li>• Horrendous amount of guilt – over their pain, situation, not helping them enough</li> <li>• There is a community of caregivers</li> <li>• Respecting the right to risk</li> <li>• Fraught with fear – making a decision about physical need – if I do the wrong thing what are the consequences</li> <li>• It’s more about increasing independence/ or maintaining independence (recovery trajectory)</li> <li>• I want to have a life like everyone around me</li> <li>• Being asked to do more medical caregiving</li> <li>• When you have someone with a MH diagnosis – fear of the police, of the ER, etc.</li> <li>• Providing education, support, empowerment</li> <li>• Needing resources to be the parent their child needs</li> <li>• Knowing who to listen to – the doctor says this, the other person says....</li> <li>• Giving up expectation/ grief/ myths</li> <li>• Being told that things are possible – the choices are the choices I want</li> <li>• Tension between liability/payment</li> </ul>
<p>Person w/ disability (acquired later in life)</p>	<ul style="list-style-type: none"> <li>• This is where I get all my information in one place – relief</li> <li>• I can get a job because I don’t have to take care of family member</li> <li>• If my family member faces a barrier- we can get an answer</li> <li>• The effort I’ve been putting forth – I might be able to get paid (relief)</li> <li>• Relief re: economic stressors</li> <li>• Don’t want to get too stressed out – need a break/respite</li> <li>• “Succession planning” – how am I going to keep my house? Etc.</li> <li>• Grief/loss</li> <li>• Horrendous amount of guilt – over their pain, situation, not helping them enough</li> <li>• There is a community of caregivers</li> <li>• Respecting the right to risk</li> <li>• Fraught with fear – making a decision about physical need – if I do the wrong thing what are the consequences</li> <li>• Overlap between the “aging” and “disability” population (it’s not silo’d)</li> </ul>

	<ul style="list-style-type: none"> <li>• It's more about increasing independence/ or maintaining independence (recovery trajectory)</li> <li>• I want to have a life like everyone around me</li> <li>• Being asked to do more medical caregiving</li> <li>• When you have someone with a MH diagnosis – fear of the police, of the ER, etc.</li> <li>• Providing education, support, empowerment</li> <li>• Knowing who to listen to – the doctor says this, the other person says....</li> <li>• Giving up expectation/ grief/ myths</li> <li>• Being told that things are possible – the choices are the choices I want</li> <li>• Tension between liability/payment</li> </ul>
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Consumer Segments	Profile
Maintaining Independence – LTSS as what helps me keep what I have	<ul style="list-style-type: none"> <li>• It will keep me out of the hospital/nursing facility</li> <li>• I can stay in my home</li> <li>• Means to independence</li> <li>• I live in a less restricted environment</li> <li>• Ages between 20-50 (adults)</li> <li>• Working or spending time doing something else – volunteering, school, sports/ desire to be active in community (varies by age)</li> <li>• Low level of baseline knowledge about services available</li> <li>• So engaged in making their way in the world that they feel overwhelmed – even those in their lives can be overwhelmed</li> <li>• Maybe more elderly – someone recently injured or with an emerging chronic/lingering health issue/ disruptive life event</li> <li>• May have a physical issue, often co-presents with depression, other emotional challenge</li> <li>• Have burned out “natural supports”</li> <li>• Look to peers to influence/inform</li> <li>• Might be getting external pressure to make a certain decision</li> <li>• Don't want to be a statistic/ a burden</li> <li>• Have some history with “the system” – can be negative</li> <li>• Want to be independent/ may be included to avoid getting help</li> <li>• May be getting input from a medical professional</li> </ul>

	<ul style="list-style-type: none"> <li>• Independence, connection to community, being active</li> <li>• Ripple effect for those who've been in the system for a long time</li> <li>• A lot of frustration</li> </ul> <p>Barriers:</p> <ul style="list-style-type: none"> <li>• Grief at the loss of independence</li> <li>• Someone else needs help more than I do</li> <li>• Feeling guilty about using something that previously you didn't need it</li> <li>• Different understanding of what independence means</li> <li>• Stigma – shame – pride</li> <li>• Sexuality, lack of information/ addressing issues</li> <li>• Don't want to be in any way of restricted environment</li> <li>• Poverty required</li> <li>• Low expectations of what you can do</li> <li>• What the consumer means by independence might not fit into the norm the system expects</li> <li>• Concerns about safety can lead to over-restriction</li> </ul>
<p>Attaining/Increasing Independence – LTSS is means improving my situation</p>	<ul style="list-style-type: none"> <li>• Finding a safe place to live</li> <li>• Not depending on friend and family/ not be a burden</li> <li>• I can get a job because I get the LTSS I need</li> <li>• Want to be more active/engaged in community</li> <li>• Increased popularity among those who get placed in long-term care facility in the greenhouse model (impact of trends in the delivery of institutionalized LT care settings)</li> <li>• Consumers who want more independence than the family is comfortable with</li> <li>• Likely more engaged/ excited/ want the change to happen</li> <li>• Prevention message might resonate</li> <li>• Transportation can be quite limited/ limits options</li> <li>• Uncertainty – is it possible</li> </ul> <p>Barriers:</p> <ul style="list-style-type: none"> <li>• Potential loss of services; timing of the loss of services</li> <li>• Loss of connections/ use it or lose it culture</li> <li>• Haven't yet had the ability to dream; may feel overwhelmed</li> </ul>

<p>Isolated/Unsupported – LTSS provides stability that is lacking</p>	<ul style="list-style-type: none"> <li>• Stability: Getting ongoing MH meds or help</li> <li>• Getting support because I don't have family</li> <li>• I feel validated – understanding that I'm not alone</li> <li>• Going to need more help getting through the process – tough to get returned phone calls (less resources)</li> <li>• Referred by human services/ protective</li> <li>• Might be homeless or living in a “cripple ghetto” - can't find anyone to communicate with; no one sticks</li> <li>• Balancing lots of different emotions (that might be in conflict)</li> <li>• Higher need for non-LTSS supports</li> <li>• Aging with a disability, things change over time, the support system you had in place at one time changes</li> <li>• May have been thrown into a situation that doesn't serve you</li> <li>• Don't have a network in place (new to state, in jail, institution)</li> <li>• The system further isolation</li> <li>• The rules don't fit – there are lots of structural barriers that make it not work</li> </ul> <p>Barrier</p> <ul style="list-style-type: none"> <li>• Balance between wanting help/ fearing interference</li> </ul>
<p>Accepting, but Overwhelmed – I need LTSS, but getting it might be harder than living without</p>	<ul style="list-style-type: none"> <li>• Knowing how to find resources for when I need them</li> <li>• This is where I get all my information in one place – relief</li> <li>• Those who have never been in the system</li> <li>• Those who've gone down this road multiple times</li> <li>• Brain injury, stress, other issues that make navigating paperwork/process more difficult</li> <li>• Non-native English speakers</li> <li>• Could have “process paralysis”</li> <li>• Don't have the bandwidth (emotion, stress)</li> <li>• Lots of fits and starts getting into the system</li> <li>•</li> </ul>
<p>Not optimally-placed current consumers</p>	<ul style="list-style-type: none"> <li>• Feeling stuck; want more independence, but it feels really not possible</li> <li>• At least I feel safe</li> <li>• Or people who aren't getting enough support to live safely</li> <li>• Reluctance/ lack of cooperation of the facility/caretakers (as a barrier)</li> </ul>
<p>Tough Sells</p>	<ul style="list-style-type: none"> <li>• It runs counter to my values (self-sufficiency, etc.)</li> </ul>

	<ul style="list-style-type: none"> <li>• Fear – asking for help = being institutionalized</li> <li>• Rural, ag</li> <li>• Elder gays (don't want anyone to know their real life)</li> <li>• People who have been chewed up by the system</li> <li>• Anti-government</li> <li>• Anti-social</li> <li>• Young adults, transitioning</li> <li>• Don't feel/ see themselves as empowered</li> <li>• Very private, can feel invasive</li> <li>• A lot of shame about your disability or situation/ pride/ self-worth</li> <li>• Being on the receiving end – have been treated in a condescending manner – negative track record when I've tried to get support before</li> <li>• If you're caring for someone, you have a dysfunctional system in place, but it's working</li> <li>• Changes might be brought about by a crisis (severe),</li> <li>• REAL fear of being “locked up” – this is a real thing</li> <li>• Peers are going to be much more likely to influence them</li> <li>• Lack of trust of the system,</li> <li>• Loss of services, fear of relatiation</li> <li>• Fear of being different from their peers</li> </ul>
Never-Wills	<ul style="list-style-type: none"> <li>• It's not for me. Period. For whatever reason</li> </ul>

Consumer Segments
Maintaining Independence – LTSS as what helps me keep what I have
Attaining/Increasing Independence – LTSS is means improving my situation
Isolated/Unsupported – LTSS provides stability that is lacking
Accepting, but Overwhelmed – I need LTSS, but getting it might be harder than living without
Not optimally-placed current consumers
Tough Sells
Never-Wills

***Which segments are we most connected to already?***

- People born into the system

***More/deeper with current segments vs. reaching new segments?***

- People trying to maintain independence (deeper with this group)

- People who are receiving services now (deeper with this group)
- People at risk for going to rehab or nursing facility (expand prevention – move upstream)
- People who want the services but don't know how to get it (avoid crises – reach them before but might be headed there)
- People who are already working- successful in the community
- Willingness/readiness

*Key criteria to select target markets*

- Ability to make a preventative impact (not only public money)
- Willingness

*Place*

- Vocational rehab
- ILCs
- CCDC, parent orgs, other grassroots, advocacy, ombuds offices
- Primary medical care – internists, gerontology, social workers, neurology
- Public Transportation – buses, bus drivers, etc.
- Congregating sites – senior centers, faith-based, fire departments (rural), farmers market (rural), Grange (rural), EMT
- Grassroots organizations: food banks, housing/human services, homeless shelters, service animal organizations, Special Olympics, domestic violence and sexual assault services
- NICU, labor/delivery, hospital case management, discharge planners
- Behavioral health clinics
- General community gathering/information points: libraries, newspapers, shopping centers, recreation centers, veterinarian offices
- Crisis centers
- Judicial system-related: courts, DOC, jails, parole officers, etc.
- Pharmacies
- Schools, CDE, Child Find, daycare/ECE organizations (early intervention staff)
- RCCOs
- LPHA
- Mandatory reporters
- Mobility specialists/durable medical equipment suppliers
- Individual mental health counselors

Market Strategies (in sequence of implementation)

- Design the NWD system to meet the needs and interests of consumer markets
- Broad public relations/awareness campaign (You're Not Alone)
- Targeted education within agencies and institutions
  - Education/information sharing strategies
  - "Top of mind" ongoing communication strategies
- Connect via other organizations with which members of the target market interact

**Linkages with Referral Sources**

*Direct Referrers (we want them to contact NWD on consumer's behalf)*

Source	What's in it for Them?	What They Need to Know about NWD to Make Appropriate Referrals
Hospital discharge departments	Cut down on readmit; want to give folks what they need - want to meet those needs; may need geographic customization - the consumer doesn't see the difference between all these service providers - we're asking people to put their reputation on the line	What their patient will get out of the system; who's paying for it; how does the connecting to services actually happen; need to see a track record of reliability; that they can call NWD in the patient's home county; figure out what it takes to build a level of trust; something that shows the path to services (visual); quick turnaround of NWD acting on the referral; statewide website and 1-800 number where they can drill down easily; a local connection
Nursing facilities	Sense of doing the right thing; there will be a shortage in some areas and that might create some incentives; may already be happening in some place; "tough cases"; they get a lot of inappropriate referrals and they want to get those people out; legal compliance	Similar to above; some regulatory changes get in the way of referrals (address structural/regulatory barrier, change the incentives/dis-incentives)
Home care agencies		
County eligibility offices	Here's there's a lot of variability how this works in the different counties; don't want to have the consumer to make another phone call - want it to be easier for their clients	

Mental health centers/ BHO	Decreased utilization rates; help stabilizing people	Similar to above
VA medical centers	Similar to hospital discharge	Similar to hospital discharge

*Themes*

- There's a need for a new system to build trust – consumers won't necessarily distinguish between NWD and the referrer; thus, NWD is relying on the referrer's credibility/integrity and that needs to be respected
- Build trust by letting direct referral sources “see behind the curtain” – be ready to answer detailed questions, to take and act on feedback, to deliver (actions speak louder than words)
- Need to distinguish which staff/levels are targeted via marketing strategies and which staff/levels are approached with a more peer-to-peer, partnership development strategy
- All will want to know: How many care managers are involved with this person?
- Need to think about the timelines from the referral source perspective

*Indirect Referrers (we want them to give consumer NWD information and explain why they should connect)*

Source	What's in it for Them?	What They Need to Know about NWD to Make Appropriate Referrals
PACE organizations	A solid reliable resource; Burned out/ hate to have to refer people to nothing/ emotional benefit; not feeling like things are being done to them; could alleviate stressors; lessen pressure on the system overall; more options to offer those who aren't Medicaid-eligible; ability to catch some folks who fall through the cracks right now	What their patient will get out of the system; who's paying for it; how does the connecting to services actually happen; need to see a track record of reliability; that they can call NWD in the patient's home county; figure out what it takes to build a level of trust; something that shows the path to services (visual); quick turnaround of NWD acting on the referral; statewide website and 1-800 number where they can drill down easily; a local connection, Regulatory changes needed; if someone is being managed with different services - and who does what for whom (to avoid duplication of assessments, plans, etc.); information they need to make sure what we offer is adding value
RCCO's		
AAA's		
ADRC's		
ILC's		
Consumer advocacy groups		
LTSS providers		
Case management agencies		
Payors		

*Themes*

- Again, there's likely a need to build trust here, in some areas more than others
- This is where things get a bit murky (some of these are doing NWD functions and those roles may shift around as the new system is implemented)
- This list ties directly to the marketing plan strategies

*Customized Referrers (we want them to customized how they refer (direct/indirect) based on the needs of individual consumers and/or to focus on referrals at key transition points)*

Source	What's in it for Them?	What They Need to Know about NWD to Make Appropriate Referrals
Schools	Address concern about "the cliff"; they get Medicaid funding (how does that play in?); a way to help have better relationships with parents/ less adversarial; consider the impacts on their budget; potential to braid; safety - if people are connected to needed LTSS, increased stability; need support to do the IEP planning (who are the right people to have around the table for that?); might relieve workload on school nurses; legal compliance/coverage	How NWD connection ties to their system - at what points (IEP, the cliff, etc.)
Local nonprofits (homeless, human services, etc.)	A dependable source of wrap-around services that complement their services/mission; to have assistance when clients are in crisis situations; being able to demonstrate how they collaborate/leverage community resources (e.g., to appear efficient to funders); data (demographics, services provided to those they refer, etc.); information about other services/agencies in their area	The specific criteria for who to refer to NWD; 24-7 access points (online, phone, etc.); most local contact point; any differences in how they have to interface with NWD for a client in crisis vs. a client not in crisis; orientation information/ materials for new employees (they have high turnover, too!); a visual quick-reference guide (one for staff, a version they can give to clients)
Behavioral health orgs	To have some assistance in getting the right service to the right person at the right time; big financial incentives to keep folks out of hospitals, etc.	

### *Themes*

- Here it's less about building trust than building awareness and informing/educating
- These should be included in the initial PR campaign
- Again, this list ties right into the marketing plan strategies

### **Other Types of Partners Needed**

- Partners to provide specialized training/content expertise to inform training
  - Cognitive disabilities, cultural competencies, etc.
- Partners to refer consumers to for peer support
- CDPHE to help unpack regulations and understand which are changeable
- Need to be integrated with other transition specialists working in other venues (DOC, other institutions) to avoid duplications and take full advantage of existing resources

### **Quality Assurance**

- Evidence based program deliver models
  - Fidelity standards
  - Enforcement/spot check to standards
  - Goals in the voice of the person
  - Models exist to be able to do that kind of assessment
- ORSSRS in the mental health arena – competency based tool

### **Other communication plan needs**

- Inter-agency relationships
- Workforce/front-line

### **Needs for Meeting 4**

- Culture change (silos to team)
- Money
- Workload/managing growth/managing change
- Workforce issues
- Training/skill-building
- Where do we fit? What's our role?
- How to leverage what works?
  - Use “how to leverage what works” as a lens
  - What are the bright spots? Within those, what's relevant to NWD?
  - What's the opportunity? What does “leverage” look like? Require?