WRAPAROUND MODEL GUIDE

For Adults with Dementia and Their Families

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I. Introduction: What the Process Is

The Wraparound process is an
individualized,
needs-driven,
strengths-based
process
for adults with dementia and their families
(modifiable for frail elderly and for older adults with mental illness).

Wraparound is a **planning process**. It is about ACTION.

The planning process identifies and assesses strengths, culture, needs, strategies (formal/staffed services and informal/natural/non-staff items), and outcomes.

Wraparound is most effective when there are **complex issues** revolving around caregiving of a person with dementia (or **frail elderly** or **older adult with mental illness** but referred to in this Manual as person with dementia) and where there may be **limited sources of support**, or a **need for a structure** for persons to provide support. With complex needs, a more **comprehensive approach** to planning includes collaboration, coordination, a team approach, and greater and more flexible supports.

Wraparound utilizes an individual and **Family Team** with team members determined by the family, often representing multiple agencies and informal supports.

The Family Team creates a highly **individualized plan** for the person with dementia and family that consists of services and supports. There is potential for a higher degree of meeting needs and achieving goals of person with dementia and caregivers because the process looks at the whole family and other supports, what is desired rather than just what the individual is eligible for and what services are offered, and where key stress and burden points are that may trigger institutional placement.

The Wraparound process is overseen by a **Community Team**. Members collaborate to help families with their individualized plans, needs and goals. Members share expertise, information, knowledge of the community, and resources. They serve as “barrier busters” in order to reach identified goals.

1.The **purposes** of creating a plan and providing Wraparound services are to:

- a. enhance the quality of life for the person with dementia
- b. support the primary caregiver and other persons providing care
- c. promote the health and well-being of the person with dementia and the primary caregiver
- d. coordinate available services and supports, both formal and informal
- e. prevent premature institutionalization

2. Wraparound Services are based on and guided by the following **best practice values and principles**:

a. individual well-being
b. family-focused, with family access, voice and ownership
c. individualized
d. strength-based
e. unconditional commitment
f. team-based
g. goal-based and outcome-oriented
h. cultural competency
i. family/professional partnerships
j. informal/natural supports and social network
k. collaboration
l. direct practice and system persistence
m. community-based
n. ensuring safety
o. cost effective and cost responsible
p. creativity

a. individual well-being

- best interest of the individual
- ensure that individual needs are met
- promote consistency and sustainability of the individual
- reduce disruption in their lives
- strengthen family relationships
- strengthen meaningful relationships
- ensure individual's voice is heard

b. family-focused

- family perspectives are intentionally elicited and prioritized during all phases of the Wraparound process
- consider strengths, needs, and outcomes for all family members
- ensure access, voice and ownership of family members
- the Family Team strives to provide options and choices such that the plan reflects family values and preferences
- recognition that family members are interdependent on one another
- help members improve relationships in order to support person with dementia and primary caregiver
- likelihood of successful outcomes is increased when process reflects individual's and family members' priorities and perspectives

c. individualized

- plans will be uniquely tailored to fit the family

- foundation laid with family voice and choice
- no two plans should look the same
- no menu of services
- review interests and preferences, as well as needs
- plan based in family's perspective about how things are for them, how things should be, and what needs to happen to achieve the latter
- be creative and use brainstorming practices to maximize options and choices

d. strength-based

- strengths are an essential ingredient in Wraparound plans
- strategies capitalize on the strengths of people participating
- demonstrates appreciation for the value each person brings to the team
- recognizes and validates the skills, knowledge, insight, capabilities, assets, and strategies that each team member has used to meet the challenges they have encountered in life
- strengths help teams focus and build on assets instead of focus on the problems or liabilities
- strengths should be reflected in all parts of the larger plan and at every intervention
- start and end meetings with the positive; celebrate successes

e. unconditional commitment

- means "never give up"
- When things do not go well or the needs of the individual and family change, the family is not dropped from service. Rather, the services and supports change.
- When faced with challenges, setbacks, or with increased challenges as the disease progresses, the team continues toward meeting the needs and achieving the goals of the person with dementia and the caregiver.
- Adverse events or outcomes indicate a need to revise the plan so that it more successfully promotes positive outcomes associated with goals
- When funding limitations or rules don't fund the type or mix of services determined most appropriate by the team, or services are not available nearby or in the community, the team must develop a plan that can be implemented without such resources.

f. team-based

- Wraparound is a collaborative process undertaken by a team
- the Family Team should be composed of people who have a commitment to the family's well-being.
- choices about who is invited to join the team are driven by family members' perspectives
- involve informal, formal, and community support and service relationships

g. goal-based and outcome-oriented

- goals and strategies are tied to observable or measurable indicators of success, which are monitored for progress with plans revised accordingly
- what does the family want in concrete terms (i.e., mom to get a good night's rest; sister to have a weekend vacation with her husband; dad to be able to talk with fellow vets; mom misses cooking; transport to appointments)
- measurable results and accountability
- how we will measure "success"
- what does the Community Team or lead agency want out of Wraparound
- outcome monitoring allows the team to regularly assess the effectiveness of the plan and to determine when the plan and its strategies need revision.

h. cultural competency

- The Wraparound process demonstrates respect for and builds on the values, preferences, beliefs, culture, and identity of the person with dementia and family, and their community.
- think beyond ethnicity
- recognizes that a family's traditions, values and heritage are sources of great strength
- get to know the family's rituals, traditions, etc.
- ask what they do for birthdays, get-togethers, holidays, etc.
- understand your own cultural issues and the impact that has on you and your perspectives
- consider how families do things as different rather than should-be-done-differently
- relationships with people and organizations with whom the family shares a cultural identity can be essential and enduring sources of support and resources.

i. family/professional partnerships

- share information to level the playing field
- no decisions are made without the family
- involve family members on all levels of the infrastructure (members of Community Teams)
- negate the idea that professionals are experts who can "fix" the family
- partnership is conducted on a mutual "No blame; no shame" premise
- strive for involvement of key players

j. informal/natural supports and social network

- primary source of natural support is the family's network of interpersonal relationships, which include friends, extended family, neighbors, co-workers, church members, and so on.

- Natural support is also available through community institutions, organizations and associations such as churches, clubs, libraries, sports leagues, or veterans organizations.
- These relationships broaden the diversity of support, knowledge, skills, perspectives and strategies available to the team
- recognize the central importance of the support that individuals and families receive “naturally” – those whose connection to the family is independent of the formal service system and its resources
- are sustainable and thus most likely to be available beyond formal services; create long-term support for the individual and family
- aide families in expanding their social network and in re-engaging natural supports that have been lost
- strive for independence of relationships beyond your guidance and empower them

k. collaboration

- each team member must be committed to the team, the team’s goals, and the Wraparound plan
- team members work cooperatively and share responsibilities
- recognize and utilize the strengths of the various community agencies
- embrace the philosophy of “our client” and decrease turf issues
- share resources and information
- engage the family in the opportunity to be part of the community
- do what makes sense and not what has always been done
- be creative in engaging useful supports

l. direct practice and system persistence

- unconditional commitment to the individual/family
- we are in this together; no bounce around; no “this is your client”
- bust barriers of the system
- fill gaps in service delivery
- change the plan if not working
- use the strength of the Community Team to address systemic issues

m. community-based

- people need a link to their home community by involvement in community life
- reduce isolation, which has probably built up
- develop comprehensive plans that utilize natural (i.e., neighbor, friends) and community (i.e., church group, gardening group, men’s coffee group, high school service clubs) supports as much as possible
- ensure service and support strategies are accessible to the family
- structure individual’s involvement in community or group activities as a type of respite

- encourage caregivers to re-connect and maintain community activities, which can be a means of support and balance in their lives
- help family members recognize community involvement of their loved one as an enhancement in their quality of life

n. ensuring safety

- priority is safety of all
- promote open and honest discussion about safety concerns
- anticipate and develop plan(s) for all potential safety situations for person with dementia, primary caregiver, and all others who impact regular support
- update with changing situations (i.e., if primary caregiver in the hospital, new strategy concerning substitute caregiver)

o. cost effective and cost responsible

- flexible (“flex”) funds should be funds of last resort
- consider the long-term effects of decisions regarding flex funds
- utilize community resources as a way of engaging the community and increase being cost-responsible
- be creative in identifying non-traditional or agency-sponsored sources
- individualize and prioritize spending (rather than dispersing funds equally across the board) as needs differ among families

p. creativity

- focus on goals and ways to meet those goals rather than eligibility and menu of available services
- use brainstorming techniques to identify new avenues of reaching goals
- think about underlying needs and interests rather than traditional services (i.e., someone to talk to vs. counselor; getting friends to help with making crafts vs. adult day center; sponge bath vs. taking a bath)

C. **Processes** of (descriptions begin on page 10):

Strengths Discovery
Life Domains
Building Teams

D. An **infrastructure** (descriptions begin on page 12):

Lead organization
Community Team
Wraparound Facilitator(s)
Family Teams

C. Processes of Wraparound

II. Strengths & Culture Discovery

Strengths are the assets, skills, capacities, actions, talents, potential and gifts in each family member, each FT member, and the community. The Strengths & Culture Discovery process identifies the assets of the family and other key supports, and builds on individual strengths and attributes toward enhanced support for the caregiver and enhanced quality of life for both the person with dementia and caregiver.

1. **Key assumptions** in Strength Discovery

    a. All people have strengths.
    b. Each person's strengths are unique.
    c. Emphasizes idea of shared responsibility.
    d. Cultures, traditions, and rituals should be viewed as strengths to respect and build upon.
    e. Sets the stage for a holistic planning process and achievement of goals.
    f. Effective Wraparound Plans use and build upon people's strengths.

2. Strengths **include**:

    a. Attitudes/Values: For example: "We take care of our own," "We are independent," "Spirituality is part of our daily life."
    b. Preferences: For example: likes to spend time alone, likes a place by the window to watch comings and goings, ice cream, no t.v. during meals, early riser.
    c. Traditions/Daily Rituals: For example: Sunday family dinners, prayer before meals or before going to bed, bath at night, decorate tree on Christmas Eve.
    d. Skills/Abilities: For example: grows roses, bakes wonderful pies, woodworking, talking to people, singing, good with numbers, organizing.
    e. Interests: For example: sports, computers, history, politics.
    f. Attributes/Features: For example: high energy, talker, pleasant smile, soothing voice.

III. Life Domains

1. Areas of daily activity critical to healthy living and successful functioning of a family.

2. Include:

    a. Medical/Health
    a. Basics of a place to live, food
    b. Social/leisure/fun
    c. Emotional/psychological/feelings
    d. Education/learning
    e. Work/employment
    f. Legal
    g. Spiritual
    h. Safety
    i. Finances
    j. Cultural
    k. Family/relationships
    l. Part of community
    m. Legacy

3. Indicate needs that are used to develop a Plan.
   Note: As a Family Team develops a Plan of Action, members/facilitator need to initially and periodically review the list of Life Domains. Safety, health and legal issues may need to be handled right away, depending on the family's situation, but plans need to soon involve expanded domains in order to address quality of life for the family.

IV. Benefits of Teams:

1. have more knowledge than any single individual
2. can help people think in a variety of ways, bringing varying perspectives
3. can improve communication
4. assure better use of resources
5. increase productivity and efficiency
6. help those involved in the family's life become interdependent with one another
7. show support for the person and caregiver
8. bring accountability; establishes who is supposed to be doing what.

Note: Teams are used for families in Wraparound because issues are complex (otherwise, just plug in service) and resources may seem limited. Teams are needed to provide the variety of perspectives, ideas, and multiple supportive resources.

D. Infrastructure

V. Lead Organization

Basically, one organization has fiduciary responsibility, though the Community Team makes decisions on use of flexible funds and family budgets. In addition, the lead organization may:

1. collect and summarize intake data
2. hire project director (suggested .10 FTE)
3. often hires lead Wraparound Facilitator (full-time)
4. often agency of community mental health services or aging network, but can be another system, such as Faith in Action, Catholic Social Services, Neighborhood Senior Services, public health agency, etc.

VI. The Community Team

Community Team (CT) members collaborate to help families with their individualized plans, needs and goals. Members share expertise, information, knowledge of the community, and resources. They view enrolled families as “our client.” They serve as “barrier busters” in order to reach identified goals. Beyond collaboration, CTs focus on the family in a person-centered planning framework; their role is to not just communicate and share resources but to also support the family’s specific needs and goals. They build “what works” and “what makes sense” into the service system.

1. **Membership**: Suggested members, representatives of:

   a. family members – current and past
   b. community leaders with interest in families
   c. often solicited from existing elder affairs community teams
   d. Council/Commission on Aging/Area Agency on Aging
   e. Alzheimer’s Association
   f. senior center
   g. hospital
   h. Department of Public Health
   i. Community Mental Health Services
   j. home health agency
   k. faith-based pastors
   l. hospice organization
   m. nursing homes
   n. Dept. of Human Services
   o. sheriff/law enforcement
   p. senior housing
   q. community meals staff
   r. volunteers organization
   s. nurse

   Others to bring in for specific issues/questions/concerns:
   a. legal services (relationship with and support of probate judge proves helpful)
   b. accounting
   c. geriatrician
   d. cognitive impairment consultant/specialist
   e. others who are not able to attend on a regular basis, but should/can be requested to attend for specific issues

2. **Attracting Partners**

   a. look for already-existing networks (i.e. Elder Affairs Network, Community Living Task Force) to build upon
   b. identify people with same values and commitment to community
   c. propose as community collaborative

- fiscally responsible venture
- pooling resources and knowledge (cost savings)
- decrease duplication in services (staff time savings)
- better support of our community members

d. less strain on community resources regarding support of caregivers (i.e., fewer ER visits)

e. market:

- attend other meetings for professionals that work with seniors in the area; introduce program idea
- mass email to identified individuals and invite to first Community Team meeting
- doctors' and lawyers' offices and hospitals
- local newspaper ads

3. **Structure**

a. Decide on chair, who does not need to be staff of agency with funding, but who is a skilled team leader.
b. Develop a Memorandum of Understanding for all CT members to reach consensus on and sign. (*example Appendix A*)
c. Decide on regular meeting schedule and length of meetings required to accomplish regular functions. Consider convenient locale and time.
d. Decide on communication process where members may quickly share information with one another.
e. Identify partners who should be engaged in CT on regular or as-requested basis.

4. **Functions**

a. Defines a shared vision and mission. Decide what can be done realistically and what the group's purpose is.
b. Target: Determines which population(s) receive priority for services, taking into consideration mission and resources
c. Members provide referrals.
d. Members share information and resources, and promote communication across levels in the community.
e. Members collaborate to help families and build systemic relationships.
f. Designs plan for community outreach, public relations, marketing and promotion.
g. Identifies funding including flexible funds, agency resources, and community resources to provide individualized services. Determines criteria for spending, what funds can be used for and what can't be used for. Creates an emergency process.
h. Keeps track of the extent and use of resources and ensures that funds are expended according to requirements of the fund source.
i. Reviews overall expenditures to identify gaps in services or needs in the community.

j. Reviews referrals presented by facilitator(s), first determining information to be submitted for review and criteria for review. CT may determine appropriateness of Wraparound enrollment, based on already-determined target priorities.
k. The Facilitator of the enrolled family presents a synopsis of new family participants and brings issues, questions, and challenges to the CT. CT members provide suggestions, resources, direction, and budget decisions for these cases, as well as for changing Family Team issues.
l. For each family, the CT reviews a Wraparound Plan developed by the Family Team. The CT reviews the plan for completeness (strengths, needs, strategies, funding, cost of services, outcomes) and the inclusion of crisis/safety plans.
m. Monitors FT plans and outcomes – are they accomplishing what they set out to accomplish?
n. Supports facilitators by troubleshooting barriers in the development and implementation of individualized plans.
o. Develops on-going training plan for the community, facilitators, family team members, CT members, volunteers, and direct care workers.
p. CT (or lead agency with CT review) develops and implements system to identify and measure outcomes (at family, community, and systems levels), including data collection and analysis. For example, a summary may indicate heavy use by adult children who are working, or high percentage of a specific trigger for nursing home placement, or enrolled families located in particular areas, or referrals from particular sources – all of which will assist CT in focus on systems issues. Adheres to reporting requirements of grants and other funding sources.
q. Looks for opportunities to institutionalize best practices and universally helpful practices (i.e., streamlining/removal of redundant steps for approvals or service delivery; communication streams among agencies; added service to accommodate common needs; make referral process more timely).
r. Identifies systems gaps (called "gap alert" by one project). For example, a CT recognized that the community lacked a needed Parkinson's support group.
s. Searches for and identifies sources of respite care, particularly for non-traditional evening and weekend stays, and those willing to drive distances in rural communities. Considers alternative means of providing respite care, such as van pick-ups at several local spots (i.e. churches) for transport to further and hard-to-travel-to sources of adult day services.
t. Creates lending supply closet and lending library.
u. If desired, creates gift packets to newly enrolled families. (*Sample items listed in Appendix B*)
v. If desired, creates packets for respite workers, with items for reminiscence, exercise, and game activities.
w. Designs and plans enjoyable group events for enrolled families. These events give families something pleasurable to look forward to in a safe setting with people who understand and accept their loved one. Creates potential for informal networking and mutual support among families. (*See Appendix G*)

5. Tips for **Successful CT Functioning**

a. Bring in major stakeholders and key partners; get the "right" people right away – those who are already involved, such as sheriff, hospital, volunteer groups, senior care providers. They want help, too.
b. Have at least core members (Council on Aging, Community Mental Health, Alzheimer's Association) have decision-making power for the agency they represent.
c. Discuss culture change, that Wraparound is a new way of doing business. Discuss philosophies and values in formation of CT.
d. Develop plan and structure for fast-track decision-making which may be needed between CT meetings. Example is selecting three core members for facilitator to call.
e. Develop a workplan for the CT: outline timeframe for initial development of mission, processes, by-laws, enrollment priorities, funding criteria, etc.
f. Set a regular meeting time and place, e.g. first Thursday of every month at 1 pm. Helps with non-core members. If several members have a regular mutual meeting, try to piggyback on it.
g. Provide education at the onset on the Wraparound process (particularly describing how Wraparound differs from case management and agency client servicing) and on the attributes of dementia, behaviors, and interventions.
h. Be clear about commitment. At CT meetings: sharing of information and resources, brainstorming solutions, providing guidance, making decisions on use of funding and resources. Outside of meetings: referrals, exploring resources, membership on Family Teams.
i. Other expectations: respect for each other and families, compassion for families and energy to help, collaboration, bringing in the voice of the person with dementia and caregivers, open and honest communication, a willingness to pursue solutions for dilemmas (and not give up nor resign to "they're not eligible"), following the Best Practice Values of Wraparound.
j. Help members understand that Wraparound is a different way of "doing business" with a different practice and mindset. If a service can take care of needs, then have that accomplished and call it case management. It's when there are complex issues and the family needs lots of support, then Wraparound is an effective service.
k. Monitor family involvement and question barriers/solutions if family members appear to be not involved. Brainstorm who else can become involved.
l. Discuss confidentiality. Families presented are not to be identified. Individual first names are acceptable for discussion. Families and their situations cannot be discussed outside of the CT.
m. Some specifics:
    - Name plates that can be seen across the table. Introduce each other for first several meetings (not just the first one).
    - Provide a binder for each member with Memorandum of Understanding, list of CT members and contact information,

copy of grant if applicable and its workplan, subsequent list of funding criteria decided upon.

- Have facilitators submit written FT updates or status reviews for CT meeting. This saves time over verbal updates on each current case and also keeps families in mind.
- Include treats/refreshments.

n. Consider periodic meetings (in person or phone) with other Wraparound projects and CTs in the state to share successes, challenges and recommendations.

6. Common **Issues/Challenges** for CTs and means of addressing

a. Members wanting meetings so short such that there is only time for presentation of new cases or issues or requests for funding, and not time to brainstorm or explore solutions and resources.

- Identify expected time and resources commitment up front.
- Ensure involvement of organizations that are already invested in Wraparound issues (i.e., sheriff, hospital, aging network) and representatives that have leeway to attend CT meetings.
- Set up times and dates that are most convenient for all or for core members. Maintain consistent date/time so members have meetings on their calendars.

b. Territoriality

- Orientation on Wraparound Model process and values.
- Plenty of discussion at outset about mission of the CT.
- Focus on “our client.”

c. Stuck on what families are eligible for/not eligible for

Set aside time to brainstorm for creative alternatives

VII. Wraparound Facilitator

The Wraparound Facilitator facilitates the Wraparound process for the person with dementia and their families. The Wraparound Facilitator is key in assisting the planning and delivery of individualized services and supports. The Wraparound Facilitator may also be called Care Coordinator, Resource Facilitator or some other term.

1. Recommended **Criteria**

   a. Facilitators can be staff of a variety of community agencies/organizations (Council on Aging, Community Mental Health Services, health organization, Dept. of Human Services, faith-based organization, etc.).
   b. Licensed social worker with Bachelor's degree in Social Work
   c. experience working with elderly population
   d. knowledge of and experience working:
      - specifically with dementia-related disorders
      - planning and conducting meetings
      - conflict resolution and problem solving
      - working with and engaging families
      - grief and loss
   e. home care management, with experience working in home environment
   f. knowledge of community resources, including formal (Council on Aging, DHS), informal (service clubs, faith-based committees), and interest groups (gardening, music).

2. **Lead Facilitator** receives referrals and makes decision on appropriateness of case, connecting with CT if unsure if referred family meets agreed-upon criteria and priorities. Assigns facilitator to family, if more than one facilitator on project.

3. **Functions**

   a. Inspires a strong, non-judgmental, family-centered approach. Respects all members and make sure everyone has a voice.
   b. Contacts the family. Explains the Wraparound process and the Facilitator's role in supporting their caregiving.
   c. Initially gets to know individual with dementia and primary caregiver(s), and builds trust.
   d. Helps primary caregiver and, if able or appropriate, person with dementia, develop Family Team (FT).
   e. Conducts intake data forms and explains benefits of collecting this information. Conducts follow-up data collection for the purpose of identifying trends, particularly in stress, burden, and use of services and supports. Also to identify effectiveness of interventions and changes in needs.
   f. Holds Family Team Meeting to get support persons together, both formal and informal supports. Makes adjustments for convenience of key members (i.e.,

working adult children) within reason, and with understanding that this an important activity to support the caregiving.

g. Conducts assessment of strengths.
h. Facilitates Family Team meetings. Makes adjustments for the culture and comfort level of individual team members. Encourages creativity in developing non-traditional ideas to reach goals.
i. Facilitator doesn't just run meetings and secure services; helps to develop relationships among people.
j. Assists the Family Team in developing an individualized service and support Wraparound plan, which is culturally relevant (that is, matches their customs and patterns) and includes crisis and safety plans. Continually encourages creativity and flexibility in guiding FT to reach goals.
k. Submits Wraparound plans to the CT for review, recommendations, and resources.
l. Advocates for the family.
m. Facilitates the implementation of identified services, supports, and interventions. The Wraparound Facilitator does not necessarily DO all activities in a plan; rather guides and helps to structure implementation. Arranges for provision of agency services and supports.
n. Identifies educational and consulting needs and arranges for these (i.e., helpful books, educational forums offered by Alzheimer's Association, computer links). Educational materials should be available but not overwhelming.
o. Provides data so that the CT can monitor outcomes of Wraparound plans and expenditures.
p. During FT meetings:
    - Serves as a model during meetings – respect members and make sure everyone has a voice.
    - To begin – Ask, "What are some good things that have happened since we last were together?" Easy, starts on positive note.
    - Periodically solicits feedback. After a couple meetings asks, "How do you think we're doing?" Gives opportunity to say how they think things are going.
    - Uses brainstorming frequently to develop multiple and creative ideas and solutions.

4. **Caseload**: Varies with Family Team status. 8-12 is deemed a reasonable amount per full-time facilitator.

5. **Multiple facilitators**

a. Recommended to better ensure sustainability of project and for mutual consultation
b. Can be from same agency or multiple CT agencies
c. Recommended: Participate in regular meetings with co-facilitators (either within project or with facilitators of other projects) to:
    - share information

- share successful strategies
- present challenging situations or conflicts and solicit ideas and advice

6. **Different functions than Case Manager**

    a. The family is the client.
    b. Potential for non-traditional hours.
    c. Focus is on goals, strategies and strengths rather than problems, needs, and services.
    d. Serves as a catalyst who assists the group to where they want to go.
    e. Direction is: How can we make this happen vs. eligibility.
    f. Looks for informal supports and strategies first vs. agency services.
    g. Team of supports tends to be more family and friends vs. professionals.
    h. Family is seen as the "expert."
    i. Actions revolve around family goals rather than "should's."
    j. Creative thinking is on-going with use of brainstorming techniques and flexibility.

7. **Challenges** and how to address

    a. If someone goes on and on – make issue into a goal ("This seems important.") List on newsprint. Ask person how do you make it better.

    b. Safety issues – periodically check if people feel safe or worried. Talk about what they are afraid of happening. What are we going to do about it (phone numbers, etc.)

    c. Facilitator doing it all (becomes case manager) – Look at issues of not having a team and discuss positives of having one and others contributing. Step back and don't do it all. Get team to clarify what is wanted, so people understand what they're volunteering for (we're often reluctant to volunteer if think it could be big commitment). Use newsprint paper so there's a visual of next steps, with who's doing what.

    d. Team getting off track – define your role in the beginning, setting the stage. "I may need to interrupt to get us back on track." ALWAYS communicate ground rules. (Trainer said whenever she assumed things were understood or thought they could go with the flow – didn't end up as well.)

    e. When people not coming up with ideas try round robin type of brainstorming. (Go around group and each member offers one idea, though they are allowed to pass. Keep going around to secure multiple ideas.) This process includes everyone. Helpful in beginning, such as when creating a mission statement.

f. Always Negative:

- Ask, “What does an ideal world look like?” and then how can we get there.
- Say, “I don’t see how this is going to get us to our goals. Maybe you can rephrase your concerns. What are you most afraid of?”
- Handle outside meeting if chronically hurting the FT.
- Acknowledge their strengths; sometimes negative people will perk up and be more positive when positive things are said about them.

g. Those who dwell on the past:

- Hear them, acknowledge what happened in the past, then talk about how this process will help us make movement toward goals.
- Say, “I’m not here to correct the past. We’re here to figure out how to move forward and make things better. We’re going to spend our energy planning.”
- Identify progress that has been made.
- Devote one session to the past, then that’s it. If there’s a need to go through this to explain how we got here, fine. Devote session to that and then not going through again.
- If they keep going back, there must be a fear – address and deal with.
- Create a symbolic ceremony of burying a past issue.

h. Those who use meetings as therapy session:

- These can lead to focus on the “why” instead of planning what to do. It’s not helpful when there’s lots of advice about what the person (caregiver) “should” do. Caregivers need positive support.
- Focus on how can we translate what’s going on into a need statement, that will lead us to strategies.
- Give homework assignment, to develop a need statement to work on.

i. Yes, but… people:

- “Okay team, we have the challenge of coming up with one solution that doesn’t have a yes, but.”
- Have this person pick one of the suggestions listed and let’s try it.

j. Quiet ones:

- Take them aside, ask what’s going on, what are they afraid of.
- Give them responsibility and report back.

k. Side conversations: Put post-it notes on a table (coffee table, dining room table), so when different conversations come up or a side-track conversation, tell them to put their thoughts on a note so we won’t lose those ideas or concerns. Thus, their issues are heard/respected.

VIII. Family Team

Family Teams (FT) are formed for each enrolled family to build on the strengths of the individuals with dementia, their caregivers, other family members and friends, and the community. The FT supports the person with dementia and the primary caregiver, along with other participants in caregiving. The Team engages in a team process with a shared mission, working together creatively to develop strategies to meet needs and produce results. The Team continues for as long as person remains at home, for continued support after death or placement in long term care facility, or until family decides adequate structure has been developed to continue on their own (though Facilitator will periodically check in as needs may change).

1. Membership

a. Includes the primary caregiver and those persons most familiar with the family plus service providers and community members. The PWD should be encouraged to identify people he/she would like to be on the FT, depending on the type and severity of dementia. The family/primary caregiver decides who should be included on the Team. The majority of team members are family members and friends.
b. Formal supports: professionals paid to provide services and supports
c. Natural/informal supports: individuals in the family's own extended family, social networks such as neighbors, church and friends, and community sources such as ministers, Bible study members, and service volunteers.
d. Often there are not as many representatives of agencies involved as there are with children's Wraparound, which may involve school and courts systems. Related agency representatives may be included in FTs because:
    - there often are few informal FT members because of isolation and few relatives;
    - varying perspectives and knowledge of resources will help in brainstorming new strategies.
e. The inclusion of the person with dementia will vary. It's important to have their input on goals, interests, and preferences. However, it is recognized that the FT meeting may be stressful for the person and/or the caregiver and other family members. Some caregivers express being uncomfortable talking about their loved one if present.
f. Team members may include those who cannot or do not attend meetings because of distance or relationship issues. These members may be involved by telephone, written communication, or one-to-one contact with the Facilitator or designated FT member. (For example, in one family two siblings refused to be in the same room together, so a third sibling who attended FT meetings communicated with the one who did not attend, updating him on progress and his assignments.)
g. Explain the benefits of teams (added supports, resources, ideas). Explain what it is not: therapy session divulging personal problems that aren't related to person's care.

h. Individuals do not need to be FT members to be included in strategies for the Wraparound Plan. (For example, a grandchild may be asked to drive the tractor with his grandfather or watch football games on Sunday afternoons together, but otherwise may not need to participate in regular FT meetings.)

i. Questions to help the person and the caregiver think about who are potential FT members:
    - When something good happens in your life, whom do you call?
    - What about something stressful or of major worry?
    - If you checked your phone bill or email, who have you been in contact within the last 3-6 months, year?
    - Who do you miss?
    - Who was a support in the past?
    - Who thinks your family members are the best ever?
    - Who will impact whether or not we meet desired outcomes?
    - Who will be impacted when we meet outcomes?
    - Think of all the areas of your life (*life domains – see page 10 for outline*). Who supports you in those areas? Do you need more support in any area?

j. New team members may be added as resources expand, persons are reconnected, and new needs are identified. The Facilitator is responsible for orienting new team members to Wraparound and assisting them to become part of the process.

k. Meetings are facilitated by the Wraparound Facilitator.

2. **Functions**

a. The FT sets goals and develops a plan to meet those goals.

b. The FT builds trust with the primary caregiver.

c. Participates in the Strengths and Culture Discovery. (Suggestion: On newsprint or paper list FT members and ask for individual strengths. Ask everyone to brainstorm for each member. (*Refer to example listing on p. 9*.) Then brainstorm ways the Team could use these strengths. Facilitator might bring this list every few months and discuss: Can we add any strengths? Have we utilized these strengths as much as we could? Are there strengths of non-FT members that we could use, i.e., high school singing group, neighborhood kids, library events.)

d. Develops a Wraparound Plan that is family-centered, promotes the interests of the person with dementia and the primary caregiver, utilizes identified strengths and interests of FT members and others, and considers all Life Domains (*see page 10*).

e. Develops crisis and safety plans for both the person with dementia and the primary caregiver. In particular, develop a plan for the possibility of illness, injury, and/or hospitalization of either. A **written form** – worked on by the FT and distributed to all members – might chart: anticipated situation or behavior (ask members for all situations they worry about that COULD happen), what we will do – to prevent from happening and also response if it happens – who will do, at what point.

f. Works to support the implementation of the Wraparound Plan.

g. Brainstorms informal and formal supports and resources. (*See Appendix C for brainstorming suggestions.*)
h. Conducts strength-based problem-solving.
i. Brainstorms options for formal respite (i.e. who drives him to adult day services which days of the week) or informal respite, such as engaging the person with dementia in community activities (i.e., garden club, men's or veterans coffee klatch).
j. Evaluates on a regular basis the individual/family outcomes identified by the Wraparound plan. ("Are our plans working? Are the services and supports effective?") If outcomes are not occurring, what changes can be made?
k. Commits to Unconditional Commitment. Sets goal of support for person with dementia and primary caregiver.
l. Identifies need for and facilitates revising the plan based on changing needs, newly identified or developed strengths and/or as the result of an outcomes review.
m. Makes provisions for long-term support of the family.

3. **Getting Started** with families and continuing

a. First visit by Facilitator should be one of getting to know the person and family, and helping them become comfortable with the Facilitator. Be prepared to explain realistic expectations of the Wraparound process and benefits to the family. Listen for supports and strengths. Get them talking and hear who they connect with and their desires, concerns, needs, hopes and dreams. People may be identified as potential FT members, those who care about the family as well as people who have been helpful to family members. Bring gift packet, if desired (*see Appendix B for suggested items*).
b. Schedule second visit soon after (within one to two weeks) to complete paper work and intake data.
c. Determine most convenient meeting time and place for FT meetings, within reason. Evenings may be needed if working members cannot get released from work; however, be careful of over-accommodating (i.e. weekend nights). Just like teacher conferences during the day, these meetings should be emphasized as important. Be creative: one FT meets at a pizza restaurant. Most FTs meet at the person's home. Consider respite care or activity for person with dementia so that caregiver(s) can focus on the team meeting. Consider refreshments.
d. Contact individual FT members before first FT meeting to confirm arrangements. Ask primary caregiver if he/she wants to contact them first or facilitator do so.
e. Meet with individual FT members by phone or in person prior to first FT meeting. Let them know what to expect and purpose of FTs. Ask for any initial concerns and ask for perspective that would be helpful as they plan. Facilitator learns what issues might come up and can be prepared (can ask, for example, "Is there anything I need to know?").
f. Third/4th visit should be a FT meeting to get all supports together and conduct a strengths assessment. The FT will:

- come up with a Mission Statement about what all will be working on together; develop a statement/description of how they wish things to be.
- look at family's needs
- come up with several different ways to meet those needs that match up with members' strengths
- identify outcomes for strategies to let members know when strategy has been successful
- team members will take on different tasks that are agreed upon.

g. Consecutive meetings should be working on a plan and strategies to reach goals. Prioritize goals (don't try to do everything at once; choose what's most important or that would make the biggest difference right now), and move through goals as each one is attained. Implement the Plan. Review outcomes and revise strategies.

h. Session agenda might be:

- Accomplishments
  ^ what good things have been accomplished since the last meeting
  ^ starts session on positive note
  ^ keeps strengths perspective (i.e., I was able to keep answering mom's same question every time for an hour, longer than I have before.)
  ^ celebrate big or small successes (i.e., my loved one sang songs yesterday)
  ^ use applause or other positive approach
- Assess progress
  ^ builds continuity
  ^ assures accountability
  ^ check if action actually done and did it help
  ^ check if team is moving towards mission and goals
- Adjust the plan
  ^ stop doing things that aren't working
  ^ use strengths
  ^ focus on needs but move closer to goals
  ^ brainstorm new strategies to meet needs if not being successfully met, or to address newly identified needs
- Assign new tasks
  ^ members take responsibility for specific actions
  ^ confirmation of who will do what toward what accomplishment
  ^ so people don't get "stuck" doing same thing over and over. For example, one week sister drives mom to adult day care, then someone else picks that up and switches tasks for set amount of time.
  ^ some people can handle doing a task for a week, or every Monday this month, where would be resistant to do so if it was forever.
  ^ reward and appreciate tasks that have been done.
  ^ develop a timeline

i. Put biggest decision-making issues in middle of meeting (think of bell curve). Members might come in late or leave early. Don't want to have to work on "heavy" issues when tired.
j. Discuss with FT realistic and useful frequency of team meetings. Meet frequently early on, every week or two weeks, to take care of immediate issues and to get a plan and support structure started. Later the meetings can be scheduled one/month or with what FT is comfortable. They may be held more frequently with changes in the individual's needs or situation (i.e. adult child goes to Florida for several months).
k. Between FT meetings: Communicate as needed to complete the tasks listed in the plan (which all members should have); follow-up with team members.
l. Establish a protocol for handling issues or emergencies/crisis between meetings.
m. Have ideas for brainstorming exercises for when FT becomes stagnant or stuck on an issue (*see Appendix C for suggestions*).
n. Bring up resource of hospice. This is a great source of support that families often do not realize they are eligible for, often earlier than they think.
o. Continue support for family in anticipation of and following death of person with dementia or placement in long term care facility. This would be in the form of the FT for continued team support and of Facilitator contact to check for caregiver needs.

4. **Keys to Success**

a. Facilitator needs to be oriented to the idea that the client is the family. Explain this concept to the family and reasons why this is beneficial to person with dementia and caregiver. Physical and mental health (especially stress and anxiety) are critical issues of support. Caregivers need to be supported in order to keep person at home as long as desired.

a. Balance formal and informal supports. Emphasis should be on informal/natural supports.
b. Meet frequently early on, every week or two weeks, to take care of immediate issues and to get a plan and support structure started.
c. Make sure family is connected to legal assistance. Many do not have durable power of attorney in place. Often preferences of the person with dementia can be secured early in the disease process.
d. Identify those families that have supports but need structure and tools to arrange those supports. These families may not need continuing FT meetings arranged by Facilitator, but should be periodically checked with for changing needs.
e. Help families focus on the positives, and help them form meaningful activities with and for their loved one. Help them re-connect socially and with the community.
f. Keep an open mind. Families have different ways of relating to each other and dealing with family issues. Assume positive intent. Respect their culture and their decisions.
g. Share your information and expertise. Also remember that family members are experts on their family and their strengths.

h. Ensure voice of everyone who is impacted by plans.
i. Advocate together.
j. Build family's confidence. Caring for someone with a degenerative disease is hard work and frustrating; what works one day may not the next day and new challenges arise each day. Accepting help from others can be interpreted by caregivers as failure. They need positive support and encouragement that they are doing a good job.
k. Keep things action-oriented and solution-focused.
l. Help FT members focus on strengths and find new opportunities to use them. (For example, just because Mary was designated as the one to handle bills, she might also want to prepare songs to sing with her father.)
m. While learning from experiences, remember that what works for one family may not work for another.
n. It takes time to build rapport and trust with families.
o. Identify and include the "family organizer" – not necessarily the primary caregiver.
p. It's helpful to include more than the immediate family and staff to bring in more and different perspectives, which helps toward creative solutions to complex problems.
q. Encourage frequent use of brainstorming. This practice promotes flexibility and thinking of whole new ways of creating new, non-traditional supports and meaningful activities. Brainstorming encourages an individualized intervention with consideration of multiple solutions and options, going beyond traditional solutions.
r. Be cautious of tendency to "fall back on" traditional case management, with arranging available services. Wraparound can be more time consuming as one is more fully and intensely involved with the family, yet outcomes should be more effective as they are targeted to the family, take into account the strengths and needs of the whole family, and move toward creative and meaningful resolution of goals. A structure is formalized that helps family members, friends, and community representatives provide available supports.
s. Be cautious of tendency to keep focusing on a few Life Domains and not expanding to cover meaningful, life-enhancing areas. Keep reviewing all domains (*see page 10*) and brainstorming ways to involve these. For example, a common response in pilot projects to questions about desired activities, both person with dementia and caregivers mention church-related activities, yet Plans rarely addressed this.

5. **Common challenges** and how to address

a. Caregiver(s) have difficulty accepting help from others; feel it is their responsibility alone; "We take care of our own;" don't want to "bother" family members and friends:
    - Talk about how this support will enhance the life of their loved one (i.e., more activities, stimulation).

- With help with tasks from others, the primary caregiver will have more time and energy to spend on enjoyable/meaningful times together with their loved one.
- People need people. Helping with socialization may be a goal. Explain why it's important for both person (continues as a need far into disease) and caregiver.
- Note the common incidence of caregivers' reduced health without adequate supports, and thus reduced ability to care for their loved one.
- Helping others in need brings satisfaction to many.
- Bring in another family caregiver to talk about their experiences with Wraparound and to answer concerns/questions. They could describe how they were struggling and how the process helped.
- Give example of another family that involved others and how it helped. They hear about real families.
- Get agreement to reconsider after three meetings after showing how meetings go (that they're not threatening or embarrassing).
- If they don't want to bother someone, ask about having them come once a month.
- One option: ask caregiver if roles were reversed, would they want their loved one doing everything themselves.

b. Caregiver(s) have difficulty accepting others into their home:
  - Members (both formal and informal) are there to offer ideas, support, resources, and expertise – not to tell the caregiver or family what to do.
  - Some may think that others will criticize their caregiving. Assure them that the plan is to build on their care.
  - Arrange activities for person with dementia during meetings if FT meeting causes anxiety for the person.
  - (See 5a above)

c. Family member uncomfortable having personal issues discussed:
  - Ask what things are okay to bring to Wraparound discussion and what aren't. This gives them control. It also identifies what they are concerned about.
  - Agree on topics (i.e., finances, embarrassing behaviors, specific people caregiver doesn't want to work with) that can be dealt with solely with the Facilitator.
  - Make it clear to all that the purpose of FTs is not to discuss personal issues but is a place for all to look at needs and decide what to do to meet those needs.
  - Set ground rules for confidentiality.

d. Family dynamics; arguing family members:
  - Talk to family members separately about the overall goal of supporting the person with dementia and caregiver(s).

- Post ground rules (i.e., talk in turn, everyone gets a say) and team agenda. Persons need to feel they're being heard and validated.
- Discuss arrangements that they all can agree to, i.e. one communicate by written communications.
- What can we agree on as a team? What can we live with?
- Focus on common grounds, such as "It sounds like we're all concerned about safety at this time of day," or "We've agreed on this activity for your dad, and we just need to work out how we're going to get him there most days."
- Identify those who are "peace makers" or who have an effect of diffusing irritants or negative emotions, and bring them to the meetings.
- Have tier 1 person physically at the meeting and communicate with tier 2 person by email or phone.
- Hold meeting at neutral location.
- Remember that you are not going to resolve decades of challenging relationships or grievances.
- The primary caregiver and family "own" the FT process and membership. If they become uncomfortable with others' continuing behavior that is rude, disrespectful, negative, or blocks progress, they may request dropping that person from the FT (after the above steps have been tried).

e. FT member doesn't follow through on tasks:

Address in progress assessment and adjust plan accordingly.

f. Lack of individuals to be on a FT, common in rural communities, and/or with elderly when friends and family have passed away, and/or where adult children have moved away; long distances; isolated. It's important to bring in more and different perspectives to develop creative solutions; otherwise it becomes professional and caregiver discussing possible services, and that's not Wraparound.

- Discuss with primary caregiver: Who would they call if there was an emergency? Who do they call when troubled – now or in the past? Who did they talk to in the last week?
- Caregivers have often become isolated while devoting time and energy to caregiving. Help them brainstorm with whom they used to socialize and means of re-connecting with them.
- Ask them about interests and things they like to do or used to do, and also person with dementia. Consider bringing in contacts related to those interests (i.e., gardening club member, veteran).
- Bring in another caregiver to talk about advantages of bringing in other people and which ones they thought of.
- Include agency referral person who already knows the situation.
- Add another professional; nurses are often "acceptable."
- Add long-distance people by phone.

- Lastly, one purpose of Wraparound is to build a social network. Therefore, you have to bring in other people to work toward that goal – and we'll help you do that.

g. Stigma of Alzheimer's disease:
  - Educate about the disease to understand that behaviors are results of damage to parts of the brain.
  - Inform about well-known individuals (actors, politicians) who have made public their family situations and have become advocates for research and dementia care.
  - Remind them that helping others in need brings satisfaction to many.

h. Caregivers are so burdened that they can't see beyond immediate crisis:
  - Help to take care of emergencies and get basic services in place, so they can breathe.
  - Help them develop crisis and safety plans.
  - Move them toward "What would a good day look like?" "What did you and (your loved one) used to like to do? How can we get some of those back?"
  - Describe how looking at strengths will help them identify new ways of meeting challenges.
  - Review times of day or certain activities (i.e. going to store, bedtime) to identify sources of highest levels of stress. Develop strategies to move High-rated sources down to a Medium or Low, using identified strengths. Facilitator aids in linking strengths to strategies. For example:
    - "John, you're good at organizing. Could you set up a schedule for X?"
    - "Patty likes to cook. Can we ask her to prepare two or three meals a week?"
    - "Let's see about an activity for Bill just for when Mabel needs to go shopping."
    - "Legal and financial issues are of major concern right now. Let's set up an appointment with an advisor in town."

i. FT gets stuck on the negative/problems:
  - Go over Strengths and Culture Discovery. Talk about these and brainstorm how these can be used to enhance the lives of the person with dementia and caregiver.
  - Focus on actions and potential solutions.
  - Select a time period in the FT meeting devoted to negative issues and problems. Allow everyone who wants to voice these. Then announce that these are getting put aside and focus now will be on identifying goals and strategies to reach those goals. If members cannot move ahead because a major problem is blocking that direction, then develop strategies to deal with that problem as a goal.

j. Family members believe that person with dementia is doing things on purpose and with intentions to be irritating, controlling or manipulative (i.e., forgetting to do something told to do, constant repetitive talking or asking the same question over, lewd/ swearing/sexual/inappropriate social behavior).
    - Arrange for education on the disease, brain damage, and resulting behaviors - by forum, written materials or internet sources.
    - Provide information specific to behaviors.
    - Arrange counseling with dementia specialist on interventions.

k. Caregiver just wants respite services.
    - Describe the benefits of developing a fuller support network (*see 5a*).
    - Engage the caregiver in discussion of goals – what would he/she really like to have happen (besides cure for dementia) regarding a better quality of life. What would that (or a "good" day) look like? Then talk about the benefits of a team, and ways the greater supports may help him/her get at least parts of that better life/day.
    - Provide some respite care so the caregiver can get some relief. Then engage in discussions about sustainable relieves.

l. The primary caregiver's health is compromised, thus potentially triggering placement of the person with dementia or creating a crisis for both individuals.
    - Develop a Safety and Crisis Plan for the person with dementia. Explore all possibilities and contingencies.
    - Develop a Safety and Crisis Plan for the primary caregivers. Explore all possibilities and contingencies.
    - Update plans periodically and as conditions change.

m. Person with dementia is a distraction during FT meetings or caregiver feels uncomfortable or guilty talking about him/her.
    - Arrange for activity for person or respite.
    - Hold meetings at a different site (i.e., coffee shop, someone else's house, Facilitator's office).

n. It's more difficult to measure progress because measurements are more subjective than for youth (more quality of life than school attendance), the disease/frailty is progressive, and placement in an institution may be delayed rather than avoided.
    - Focus on goals and attainment of those.
    - Focus on quality of life and stress reducers.

6. Examples of **personal Wraparound stories**

a. One family requests visits by someone who speaks Finnish. Individual's wife reports that he is in a better mood and more animated for several days after he is able to talk to someone in his native language.
b. Recipient was not aware of potential safety concerns. She and her neighbor check on each other daily to make sure everything is going all right.

c. A mother with dementia fell and broke her hip, and had surgery and rehabilitation. She was discharged to her son’s home. With help from seniors organization and supplies from Wraparound Lending Closet, he is able to manage her care at home.
d. A spouse caregiver was not able to get sleep because her husband would wake up during the night, wander and become agitated. A schedule was set up where the adult children took turns spending the night.
e. A former farmer wanted to drive his tractor. The family arranged with a family friend’s son to come over and the two of them drive around the fields together.
f. Two sisters would not speak to each other but were able to communicate individually with the FT to cover responsibilities.
g. A group of friends was organized to visit with the person with dementia so that her husband could go out with his friends for coffee, something that has been part of his routine for many years. The wife’s friends were more comfortable visiting as a group (often friends or volunteers worry about what to do if something happens and they’re there alone), and the husband always has coffee and donuts/cookies for them.
h. The person with dementia ladles out oatmeal or soup at a Homeless Shelter. She senses that she’s helping others, she keeps busy, there are people there who watch over her and don’t mind her questions, and her daughter does errands during this time.

IX. Plans

1. Persons – with dementia, old age, frailty, physical illness, or mental illness – continue to **express needs for**:

   a. meaningful relationships
   b. affection
   c. sense of safety, security and well-being
   d. stimulation
   e. power and control
   f. joy
   g. release from pain and discomfort
   h. sense of value and self-worth

2. Are **based** on:

   a. strengths
   b. needs
   c. individualization
   d. family goals
   e. blend of formal and informal resources

3. **Needs and Services are different**:

   a. someone to talk to vs. therapist
   b. recognizing that there are others who share similar issues and concerns vs. formal support group
   c. short-term relief from caregiving responsibilities vs. adult day services
   d. feeling needed vs. being kept busy

4. **Good plans**:

   a. are practical
   b. use all available resources
   c. build on strengths
   d. are action-oriented
   e. provide clear outlines and expectations of who does what when
   f. improve the quality of life of family members
   g. move everyone toward attaining identified goals
   h. go beyond what we have always done

5. Plans move toward **Outcomes**, statement of which:

   a. families identify for themselves
   b. are based in the life of the family
   c. describe how we will know life is better

   d. need to be positively stated
   e. are simple enough anyone can understand
   f. reflect the concerns of the team
   g. are measurable
   h. You should not try to re-write or paraphrase what the family members say, but you should always try to get at the positive result.
   i. The idea is to determine if what we are doing makes a difference and gets us closer to our stated goals, not to measure how hard everyone is working.

6. Examples of **Outcome Statements**:

   a. When we have our extended family over for dinner, they will stay the entire time.
   b. When I finish the quilt I have been working on for several years.
   c. When my loved one does something and I know what to do about it or who to call.
   d. When I talk with my best friend and we laugh.
   e. When mom gets a good night's rest and is rested for the next day.
   f. When I remember and cherish the memories.
   g. When my loved one laughs.

7. Creating the **Action Plan**

   a. View it as a blueprint for change
   b. A way to coordinate greater support; share the care
   c. Use strengths inventory to help brainstorm creative options for addressing key needs
   d. Try for at least two informal options for every formal one suggested
   e. Be prepared for needs to change

8. Include planning across all **Life Domain** Areas

   a. emotional/psychological
   b. health
   c. education/vocational
   d. financial/legal
   e. residence/home
   f. social/recreational
   g. family/relationships/part of community
   h. spiritual
   i. legacy

9. Include a **Crisis Plan** that is intended to help prevent a crisis and also to deal with the crisis when it occurs.

   a. "Crisis" is defined by the individual, caregiver, family, and FT.
   b. The Crisis Plan should include the availability of around-the-clock response.

c. For this target group, set up a plan for the possible illness/hospitalization of the person with dementia as well as major caregivers.

d. Identify potential triggers of crisis:
    - change in routine
    - too much activity
    - not enough activity/boredom
    - overwhelming demands on person with dementia and caregiver
    - confusing demands on person with dementia
    - lack of sufficient sleep/rest
    - injury
    - access to weapons and machinery
    - lack of safety features
    - reaction to or side effects of medications
    - illness
    - change in schedules of support persons
    - move

6. Have a **Safety Plan** that is intended to insure the safety of the person with dementia and caregivers.

a. Should provide for round-the-clock response in the community.

b. Is reliable, makes sense, realistic (i.e., Can we really rely on neighbor Joe to be there most of the time and able to get over here quickly?)

c. Strategies are across environments (plan for home, plan for in the car, plan for the grocery store, etc.)

d. Changes with changing situations (i.e., person now wanders where didn’t before; live-in grandchild moves out)

e. Should be written down and distributed

To Summarize:

Start With: →	Use: →	For: →
Family Needs Family Culture Individual Strengths	List of what areas trigger high, mid, low levels of stress Strengths Discovery Brainstorm	All Life Domains Support Plan Safety Plan Crisis Plan

List all/Brainstorm: →	Prioritize: →
Informal/natural supports Agency services Community resources	Safety/Crisis Plans What will give breathing space What will have biggest impact What will mean the most to family

Outcome statements:
Outcome Scale Sheet to monitor what will be done by whom by when

Questions to Ask:
Does this Plan reflect the family's preferences and choices?
Does this Plan "fit" the family's culture?
Is it positively stated?
Does everyone know what to do, who does what when, with what intended results?
Can we tell when goal(s) is achieved?

When: →	
1. Needs change 2. Supports change 3. First priority goals achieved	Revisit Plan Start Over with new goals

X. Training

1. Education about **Alzheimer's disease and related disorders** is imperative for family members, facilitators, and volunteers/respite care workers. This information helps caregivers understand behaviors and recognize interventions (things they can do) to prevent, reduce and diffuse agitation, confusion and distress. This is tremendously supportive in itself. Facilitators report that often caregivers do not know that what the person with dementia is doing or not doing is a result of the disease – not because of manipulation by the person or something lacking in caregiving. Provide initial, basic information about the disease and brain changes at the beginning, and periodically for incoming enrollees. Materials are helpful (*see Appendix D for suggestions*), but often books and other lengthy material are overwhelming to the caregiver. Face-to-face training provides the opportunity for questions pertinent to particular situations. Education on the disease improves care by paid and volunteer workers as they gain understanding on what to expect (generally) and ways to handle tasks or behaviors. Educational forums may be available from the local Alzheimer's Association Chapter offices or community college faculty.

2. Wraparound **Facilitator Training** is provided by Michigan Dept. of Community Health's Division of Mental Health Services for Children and Families. This training explains the structure, overall values, and roles of Wraparound entities. This is mandated by Children's Wraparound Services and can be available to facilitators for older adults with dementia and their families, depending on arrangements with MDCH's Division of Services for Children and Families. It is possible to extrapolate and adapt key points for Wraparound for adults. Arranging for Wraparound Facilitator training with a trainer who has experience with adults and uses these examples is helpful and will be developed with MDCH (cameronm@michigan.gov).

a. Training includes:
  - Best practice values and principles
  - Engaging families
  - Strengths Discovery
  - Culture
  - Family Team development
  - Benefits of teams
  - Developing vision and mission
  - Life domains
  - Needs vs. Services
  - Prioritizing needs
  - Action plans
  - Getting to outcomes
  - Effective outcome statements
  - Crisis and safety planning
  - Support plans
  - Responsibilities of CTs

        - Outcomes and evaluation

    b. Include family caregivers in this training. Present a concept/topic/major concept, then have each small group within the training (say, 5-6 people) work with their family member in their real-life situation (i.e., design a mission statement, have family member identify needs then prioritize, etc.).

3. Training about the **concept of Wraparound process, values, roles and responsibilities** should be provided to Community Team members and Facilitators. Most of the information for such training is covered in this manual. Experienced facilitators, along with family members, should provide both Wraparound cases and exercises to give a better sense of how the process works.

4. **Further** training is encouraged on such topics as:
    a. Developing and Facilitating Family Teams
    b. Brainstorming and the Wraparound Process
    c. Developing Outcome Driven Plans
    d. Crafting Creative Interventions Using Strengths and Needs
    e. Culture and Strengths Discovery

5. Further **education for family** members:
    a. legal and financial considerations and decisions
    b. grief and loss
    c. problem-solving skills
    d. relationship role (i.e. spouse, daughter) mixed with role of caregiving (Savvy Caregiver is an evidence-based example)

6. **Counseling** on specific family issues by dementia expert
    a. found to be very helpful by family members and facilitators but incurs added expense
    b. one-on-one sessions with family members; include the facilitator or another FT member for back-up and because the primary caregiver may not remember all that was discussed or suggested
    c. can be helpful as a resource for facilitators to get assistance (present cases at a joint facilitators meeting) with especially challenging family situations.

XI. Evaluation

The Community Team monitors and evaluates attainment of goals.

1. Individual/Family Level

a. Plan is developed for each family that is:
   - action-oriented
   - unique to each family
   - family-focused
   - uses a balance of formal and informal supports

b. Goals and outcomes of primary caregiver and family are identified and achieved.
c. Goals and plans change as needs and resources change.
d. The family expands its supports network and builds a structure to ensure supports.
e. The family's educational and skill needs are identified and provided for.
f. Goals are achieved across all life domains.
g. Quality of life for person with dementia and caregiver are enhanced.
h. Problem-solving capacity is increased.
i. Crisis and Safety Plans are designed.
j. Physical and mental health of person with dementia and caregiver are maintained and distress is reduced.
k. Person with dementia is not prematurely institutionalized. A question that can be asked at baseline/enrollment and at 6 month intervals, is: "What do you think will be the deciding factor or tipping point in placing your loved one in a long term care facility?" Some caregivers may say they never intend to do so, but many will identify factors, such as declining health for themselves, person with dementia becomes bedridden, etc. These identified factors can be targeted and addressed as Plan of Action goals. They can be used as a gauge to see how well the Wraparound process has helped to prevent or delay institutionalization.
l. Facilitator might use a standard screening tool for burden or stress at baseline enrollment and at 6 month intervals to determine (hopefully) lowering or maintaining as disease progresses. Items that continue or increase may be targeted for Plan of Action. Suggested tools are fairly brief and can be completed either by primary caregiver and reviewed with Facilitator or each question asked by the Facilitator.
   Suggested tools include (*which can be accessed via internet*):
   - Zarit Burden Interview
   - Geriatric Depression Scale
   - AMA (American Medical Association) Caregiver Self-Assessment Tool
m. Satisfaction Surveys for all Family Caregivers were developed by pilot Wraparound projects and mailed/phoned and summarized for the CT every 6 months.

Examples of Satisfaction Survey Questions (*some with range of Strongly Agree to Strongly Disagree; others open-ended*):

- My referral was responded to in a timely manner.
- I was treated courteously and with respect.
- The meetings focused on our family's strengths.
- My input and contribution were requested.
- The Wraparound team reviewed progress on our goals.
- The Wraparound team has made progress on our goals.
- I was provided enough information to improve my ability to care for my loved one.
- As a caregiver, my quality of life was improved because of the support I received.
- The program is/was helpful to me as a caregiver.
- The program is/was helpful to my loved one with Alzheimer's/dementia.
- I feel that I will be able to respond to future difficulties by having Wraparound services.
- What has been most beneficial or helpful to you?
- Has the quality of life improved for you?
- Did this process help with prolonging nursing home placement?
- What do/did you like most about the project?
- Name one thing that would help improve services?
- Do you feel the level of services met your family's needs?
- Comments

2. Agency/Community Team Level

a. Commitment is made to Wraparound Best Practices, Principles and Values
b. Key stakeholders and resources are brought to the table
c. Provide for families through teams made up of formal and natural supports
d. Remove barriers to achieving family goals
e. View family as "our client" and move beyond agency territories
f. Monitor Family Teams for completeness and voice of the family
g. Share resources and information
h. Monitor intake data to identify users of Wraparound and trends.

3. Systems Level

a. More efficient and effective delivery of services
b. Systems are coordinated and barriers/silos removed and worked through
c. Community's families in need are supported and assisted to improve care
d. Funding for care and services is streamlined, adequate, and monitored for best use
e. Gaps in services are identified and filled

XII. Appendices

2. Sample Community Team Memorandum of Understanding

(adapted from Ionia County Community Mental Health's Forget-Me-Not WrapAround Community Team)

As a member of the Wraparound Community Team, I embrace the use of Wraparound processes for people experiencing the effects of Alzheimer's disease or related diseases in their families and am committed to promoting Wraparound services that are family-centered, strength-based, promote access to quality services that are responsive to their needs, and lead to higher qualities of life for both the individual with dementia and their caregivers.

All members agree to:

- Identify and seek permission to refer families that have complex needs due to a family member experiencing severe behavioral symptoms as a result of dementia.
- Utilize or promote the use of Wraparound practices during the provision of service to individuals with dementia and their families.
- Participate in Wraparound Community Team meetings.
- Work together to coordinate ease of access, assess gaps in services and avoid duplicative service provision to individuals with dementia and their families.
- Plan, provide, promote and/or participate in education or trainings related to people with dementia and their families, particularly those with complex needs.
- Promote services that delay or alleviate the use of institutional care for individuals with dementia.
- Disseminate brochures and literature regarding the Wraparound initiative, dementia and related issues.
- Recruit and/or identify potential community volunteers to participate in the Wraparound project.
- Support the person with dementia and their caregivers through transitional phases of the illness.
- Promote and honor confidentiality of individuals with Alzheimer's disease or related diseases, their families and other caregivers.
- Respect fellow members and their ideas and contributions, individuals with dementia, their families, and other caregivers.
- Bring a voice to the table of someone experiencing the effects of Alzheimer's disease or related diseases themselves or as a caregiver.
- Promote open, honest communication with all Community Team members.

This Memorandum of Understanding was written to promote the county-wide collaboration and partnering efforts necessary to support the activities of the Wraparound Initiative for Adults with Dementia project, implementation date ___.

Signatures

My signature signifies that I am in agreement with and will follow the above provisions.

(Note: multiple lines follow for all signatures on one sheet)

3. Sample Wraparound Program Service Agreement

(adapted from Alzheimer's Association-Greater Michigan Chapter, Upper Peninsula Region Wraparound Program)

The mission of the __________(name of lead organization) is "To ….." (Note: Place organization's mission statement here.)

The Wraparound Program is offered by the _____(lead organization). The purpose of the Wraparound program is to assure access to a full range of education, care and support services for individuals with dementia and their caregivers. Wraparound will work with individuals and families to prevent unnecessary or premature nursing home placement, to keep individuals living at home as long as possible, and to help individuals and their caregivers achieve individual and family-desired outcomes and thereby increase their quality of life.

Wraparound is a voluntary program and by signing this agreement the individual and family/caregivers agree to the terms and expectations of the program. These include but are not limited to the following:

- Provide verification of diagnosis (needed to determine eligibility) (*NOTE: this requirement was not made of other projects*.)
- Develop a Family Team which may consist of family members, friends, neighbors, service providers, and others interested in planning, support and care of: ____________________ and primary caregiver(s), along with the primary caregiver and Wraparound Facilitator.
- By signing this agreement I/We consent to the sharing of information with the Wraparound Community Team – though full names and identifiers will not be used for confidentiality – for the purpose of determination of eligibility, planning, and identifying community resources. I/We further consent to the release of non-identifying statistical information to ___ (*in cases of grant funding*).
- Complete necessary release of information forms, reimbursement forms and other necessary paperwork for the purpose of planning and efficient delivery of services.

I/We understand that this agreement can be withdrawn at any time and that I/we can withdraw from the program at any time.

The ____(lead organization) will maintain individual and family information in confidence and will not release it without the separate expressed written consent of the individual/family.

This agreement is entered into this date:

Individual
Caregiver/Authorized Party/Guardian
Wraparound Facilitator

Appendix B:
Items for Families

1. Family Gift Packet Items

An option to give newly enrolled Wraparound families.

a. “Understanding Difficult Behaviors” book (see Resources)
b. “Share the Care” book (see Resources)
c. “The 36-Hour Day” book (see Resources)
d. Informational material from Alzheimer’s Association, including “Caregiver Guide,” Safe Return program, and upcoming education forums
e. File of Life Information Pack
f. List of local senior resources
g. Magnetic memory frame
h. Magnetic erasable memo board
i. Marketing pieces from agency(s) such as pen, magnet
j. Sample cleaning products that do not require water (received free samples from companies): No Rinse Shampoo, body wash

2. Lending Supply Closet

a. Suggested items to have available to lend to families as needed, and then are returned when no longer needed:

- wheelchairs
- walkers
- commodes
- shower chairs

b. Items to collect to have available for families in need:

- blue pads
- adult depends
- waterless shampoo
- shampoo caps
- wipes

Appendix C: Brainstorming

Brainstorming is an essential element of the Wraparound process because of the need to find creative solutions to complex issues. It's a means to get beyond what families are eligible for, which does not necessarily meet their needs. Hearing someone else's ideas spurs others to build on those. This is why different perspectives are helpful: hearing ideas we may never have thought of on our own and also creating many ideas, which is the way to find the best ideas. Brainstorming and Creative Processes facilitate group interaction, consider multiple solutions and options, provide a means to spur creative thinking and create breakthrough ideas.

1. When to do brainstorming:
    a. After settling in, maybe about one month, the FT may brainstorm to get to a needs statement, which gets the team to their mission and goals.
    b. When stuck on a problem or can't come up with strategies. You can refer to beginning: "Remember when we did this, we came up with…"

2. Brainstorming Rules
    a. Do not evaluate member ideas.
    b. Record all ideas in a central location.
    c. Include the wildest ideas possible.
    d. Generate as many ideas as possible.
    e. Combine and build on existing ideas.

3. Stating the problem or goal needing a solution
    State in the form of a question: How can Mom get a good night's sleep on a regular basis? How can we get Dad to day care services at least 3 days a week? How can Mabel go to church and be assured that Harold is safe?

    NOTE: Make sure the stated goal is not actually one strategy to a goal: How can we increase respite services? is actually a strategy to a possible issue: How can Dad get more rest or How can Dad get a break from caregiving so he can visit with his buddies?

4. Brainstorming Process:
    a. Gather the group of people (FT or CT) to address the situation
    b.Establish the ground rules
    c.Generate as many ideas as possible - at least 10. Note: moving past a typical 6-7 ideas to at least 10 generates the most creative ideas.
    d. Designate one member to record each idea that is put forward
    e. Withhold criticism or challenges to any of the ideas put forward, however impractical or irrelevant they may appear to be at first – especially, "That won't work," "She'll never go for that," or "That's too expensive." These may prove to be the most viable ideas as they haven't been thought of before. The Facilitator

needs to be vigilant about curtailing criticism and negative reactions to ideas at this point.

f. If members are stuck for ideas, try a lightning round robin: go around the group and each member throws out something, even if wild and crazy.
g. When a list of 10 or more options has been developed, move to choose those that make the most sense:
    - Identify those that have the best potential. What will get us the biggest impact? Come up with ones that everyone can agree to try.
    - From those, choose the ones that most closely tie to strengths.
    - Work toward consensus: All can live with it.
    - Criteria-based ranking: prioritize ideas after agreement on criteria
    - If need to vote, family gets the most votes.
h. Review decided-upon options
    - Does each option fit with the stated need?
    - Does each option build on strengths?
    - Is responsibility shared?
    - Is it clear what we hope to accomplish and what desired results are?

If the family knew what to do or only one option makes sense or the family was eligible for services that fit their needs, then the family would not need Wraparound. Creativity and flexibility and use of everyone's strengths (family, friends, professionals, community entities) are hallmarks of Wraparound. Brainstorming is a means of flushing these out.

Appendix D:
Resources

Share the Care, How to Organize a Group to Care for Someone Who Is Seriously Ill, Capossela C and Warnock S. Simon & Schuster.

The 36-Hour Day: **A Family Guide to Caring for Persons with Alzheimer Disease, Related Dementing Illnesses, and Memory Loss in Later Life,** Mace,N. and Rabins P. Baltimore, MD: Johns Hopkins University Press.

Mental Health & Aging Project, Lansing Community College: www.lcc.edu/mhap
Offers education, training and consultation for those who work with older adults with mental illness, dementia, and/or others with developmental disabilities in a wide variety of settings. Available free-of-charge:

1. Print and video library on aging and mental health topics.
2. "**Caring Sheets: thoughts & suggestions for caring**," Weaverdyck, S. Includes factual sheets on the brain, information about various diseases causing dementia, and intervention techniques
3. UPDATE newsletter: technical assistance resources for mental and aging professionals.

Understanding Difficult Behaviors: some practical suggestions for coping with Alzheimer's disease and related illnesses, Robinson A, Spencer B, White L. Ypsilanti, MI: The Alzheimer's Education Program, Eastern Michigan University. 734-487-2335, www.emich.edu/alzheimers.

Resource Guide to Wraparound (Children's) at www.rtc.pdx.edu/NWI-book/indix.shtml

Michigan Dementia Coalition: www.dementiacoalition.org. Available to download:

1. Michigan Education and Training Programs Directory (listing by county)
2. "Knowledge and Skills Needed for Dementia Care: A Guide for Direct Care Workers in Everyday Language" A guide for direct care workers to identify the knowledge and skills they need to provide quality care for a person with dementia.
3. "Research-Based Recommendations for Effective Caregiver Interventions"

Alzheimer's Association: www.alz.org; 1-800-272-3900 for resources including fact sheets, education, and support groups.

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Dementia Care Program Consultant and Wraparound Project Director
Mental Health & Substance Abuse Administration, Michigan Department of Community Health
Technical assistance, consulting

Appendix E:
Funding Sources

1. Additional funding may be needed to **cover**:

    a. salary of Wraparound Facilitator(s) if this extensive family servicing is outside/beyond the organization's "regular" servicing.
    b. flexible funds for family needs not covered or available from other sources
    c. training
    d. respite care for families that is not covered or may be too expensive for families

2. Some **possibilities** of funding sources:

    a. United Way
    b. Senior Millage
    c. Community Foundation
    d. local businesses
    e. organizational line item
    f. family caregiver grant
    g. Area Agency on Aging/Council or Commission on Aging
    h. Veterans Administration
    i. MDCH Community Mental Health Block Grant funds (if meet criteria of seriously mentally ill, dementia with delusions, dementia with depressed mood, dementia with behavioral disturbances, or co-occurring disorder of dementia with mental illness or progressive, disabling medical conditions)
    j. Community Team members or core members pool funds for family flex funds
    k. education/training from:
        - Alzheimer's Association
        - Community college
        - County extension service
        - Hospice organization
        - Pro bono by local legal organization/lawyer
    l. Medicare (http://wpsmedicare.com/part_b/business/add_chng_report.shtml)

Appendix F:
Ideas for Marketing

1. **Market Needs**: According to the ***Alzheimer's Association's 2008 Facts & Figures***, (*see this material at www.alz.org for more supporting statistics*):
    - a. Approximately 5.1 million Americans have Alzheimer's disease or related illness. Approximately 10% of persons age 65+ and nearly half of persons age 85 and older have some form of dementia; these numbers will increase with the aging of the Baby Boomers.
    - b. Approximately 70% of care of persons with dementia is conducted by family caregivers. One quarter of these provide 40 hrs/week or more of care and many (a third) do so for five years or more. The health and well-being of these unpaid caregivers is compromised by the strain and stress of caring for someone with dementia.
    - c. The average cost of nursing home care is $70,000/year. This cost can be alleviated by delay of placement through support of family caregivers, one avenue of which is the Wraparound structure which capitalizes on both formal and informal supports, thus making the most of limited community and state resources.

2. **Target Markets**
    - a. business people from downtown businesses and professional buildings
    - b. senior centers
    - c. primary care physicians
    - d. service organizations such as Kiwanis, Lions Club, etc.
    - e. local, county and state police and sheriffs' offices
    - f. courts, justice departments
    - g. departments of health, human services, community mental health
    - h. senior housing
    - i. nursing homes: admissions, social workers, administrators
    - j. home health care agencies
    - k. hospice organizations
    - l. hospitals, particularly discharge personnel
    - m. Alzheimer's Association
    - n. Area Agency on Aging and Commission/Council on Aging
    - o. churches
    - p. families who use senior center
    - q. support groups
    - r. emergency and ambulance services
    - s. library staff and boards

3. **Tools**
    - a. brochure: a simple flyer describing program, benefits of enrolling, sponsors and contact information
    - b. newspaper ads, press releases and feature articles
    - c. community access television

d. radio interviews
e. public service announcements
f. individual contact with board members and leaders of above markets
g. feature articles on events for Wraparound families (*see Appendix G*)
h. newsletters
i. educational forums
j. health/senior/county fair booth
k. websites of all CT member organizations

Appendix G:
Special Events

Wraparound projects are encouraged to develop special events for enrolled families so that they have social events and something to look forward to. The events are “safe” in that others are bringing their loved ones and those attending are supportive.

These events are occasions to recruit community volunteers for one-time contributions. Groups such as community bands, high school singing groups, and crafts people are great sources for bringing music and other interests.

Secondary outcomes include:

- local news and photo opportunities (of course with permission requirements) promoting the program to the community
- informal networking and sharing among families
- opportunities to provide additional, brief education presentations and materials; for example, at one event the regional Alzheimer’s Association representative was available during the event for questions.

Examples of successful events:

1. summer picnic at a park
2. pastie meal (U.P. specialty dish)
3. December holiday party with caroling and dancing
4. men’s (caregivers) luncheon get-togethers
5. day camp: One project does not have a day care facility in the entire county and in-home respite was not readily accessible in a very rural area. The two-week day camp was developed to help with this issue. Held at a local school in the summer, activities Monday-Friday included: sing-a-longs, exercise, music therapy, hand massages, story telling, antique tractor and car clubs brought to view, scrapbooking, horseshoes. Retired nurses and CT members volunteered, and businesses provided articles for bingo prizes, plus a family dinner picnic. It’s a lot of work to plan and basic education on dementia was held for volunteers.
   Monthly day camps are continuing through the year, with local school and other community groups joining in.