

Support-Staging Model for Caregivers of Adults with Intellectual Disability Affected by Dementia



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Rationale

Like other families, the parents, siblings, and other family members or significant others, of adults with intellectual disability (ID) are concerned about the onset of new symptoms, needs for validation of conditions, and how to seek advice on caregiving. The main difference is that these families are in a sense “perpetual caregivers” who have looked after or supported their relative over decades, first as a child, an adolescent, then a young adult, and now as an older adult. With the onset of new symptoms which lead to a compromise of effectiveness, memory, and general functioning, new challenges come forth.

Looking toward support systems, families reach out to experts, familiar faces, and others who can help with these new challenges. Agencies providing dementia supports often encounter families who have been effective caregivers over the lifetime of their son, daughter, or other relative, and find them vexed by what they are encountering. Management of help for such families has been the subject of much discourse, as it is well known that – as in the general population – care is not homogenic and what caregivers need as help will vary according to several factors. These factors may include family history and awareness of lifelong development, familiarity with dementia symptoms and their implications and trajectories, and options for supports available for caregivers of persons with dementia.

To address these factors and to define a dynamic process for providing aid consistent with needs, a working group associated with the 2016 International Summit on Intellectual Disability and Dementia held in Glasgow, Scotland (Watchman & Janicki, 2018) noted that it was necessary to identify an organizing scheme. The group proposed using a staging scheme to organize the assessment of needs and help with planning aid for families (Jokinen et al., 2018).

Such a scheme would help with the clinical assessment of what stage a family may be in so that targeted services might be most efficacious. To assess the schema concept, it was proposed to undertake a project that would use a family help/ counseling approach utilizing the evidence-based New York University-Caregiver Intervention (NYUCI) to see if a support staging model assessment might help focus on what specific aid a family may require to meet caregiving needs.



<https://www.the-ntg.org/glasgow-summit-on-id-dementia>

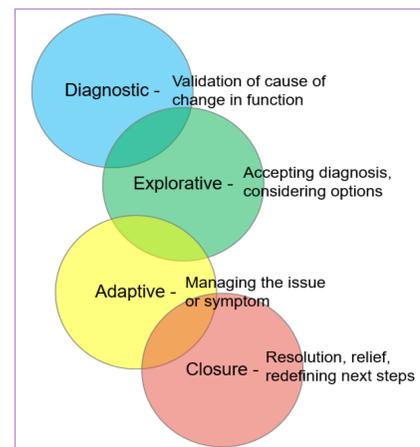
Purpose

Using the Jokinen et al. staging scheme, the project would operationalize a support-staging assessment instrument which would enable counseling staff to frame the state of a family's concerns, build relationships through this knowledge of the caregiver, and then provide tailored services. The outcome will enable systematic coding and organizing both objective and subjective data so that specific interventions and counseling can be adapted to meet both intermittent and continuous caregiver needs.

The Caregiver Support-Staging Model

The model has several components:

- The **first aspect** is recognition of the role and nature of the involvement in caregiving, which can be either *primary* or *secondary* – or both over time.
 - primary involvement** is when the caregivers provide direct care and have support responsibilities when persons affected by dementia either live with their caregivers or are otherwise under their direct supervision and personal care.
 - secondary involvement** is when the person lives elsewhere, separately from the family caregiver, and care does not necessarily include direct interaction, but may be more focused on advocacy, oversight, and planning.
- The **second aspect** is the influence of staging - dementia caregiving may see caregivers move back and forth between the phases of the support-staging model, which include ‘Diagnostic’, ‘Explorative’, ‘Adaptive’, and ‘Closure’ aspects.
- The **third aspect** is the differentiation between *objective* and *subjective* needs.



Objective Needs	Subjective Needs
<ul style="list-style-type: none"> Knowing signs and symptoms Diagnostic advice Understanding changes and managing behavioral issues Adapting the home Planning for future Finding and navigating resources Responding to end-of-life care needs 	<ul style="list-style-type: none"> Being informed at diagnosis and over course of dementia Coping with loss and fear of future Difficulties planning for care Accessing community-based coordinated services Partnering with medical professionals Overwhelming care demands Sense of isolation and abandonment

Hypothesized Application

Table 1. Support-staging model of family-based caregiving in intellectual disability

Dementia support stage	Care factors and support	Outcomes/goals
(1) Diagnostic Phase (seeking validation of the cause of change in behavior and/or abilities)	<ul style="list-style-type: none"> Conferring or seeking help in understanding changes in behavior and function Seeking diagnostic source and following through on diagnostic requirements 	<ul style="list-style-type: none"> Validating suspicions Tracking behavior and function Engagement in assessment and diagnostic process Obtaining a diagnosis Better understanding of disease and its progressive nature. Plan of care formulated with persons affected Advanced care directives identified Treatment decisions Linkages to agency services
(2) Explorative Phase (accepting the diagnosis and considering support options)	<ul style="list-style-type: none"> Being informed and educated about dementia and comorbid conditions Understanding information on diagnosis and its implications Talking with adult about diagnosis Getting information on care practices Planning for future care needs 	<ul style="list-style-type: none"> Alternative living arrangements identified in event needed Home modifications implemented Routines and tasks adapted to reflect changes Service adaptations made to accommodate family needs Respite instituted Coping with changes Involvement with support groups Better quality of life
(3) Adaptive Phase (managing symptoms of dementia)	<ul style="list-style-type: none"> Monitoring behavior and function Adapting care practices to changes in behavior and function Getting ongoing advice for supports and home modifications Self-care strategies Psychosocial counselling including grief and loss 	<ul style="list-style-type: none"> Setting located for care including advanced care as needed Supportive services engaged End of life decisions are respected Celebration and appreciation of life moments Caregiver reflection on experiences and moving forward in life
(4) Closure Phase (resolution of caregiving issues, sense of relief, satisfaction, peace of mind and redefining next steps in life)	<ul style="list-style-type: none"> Completing plans and works to address issues Obtaining supports and services needed. Understanding end of life issues Supporting end of life decisions Accepting and moving on Obtaining bereavement / grief and loss supports 	

Adapted with permission from Jokinen et al., 2018.

Outcomes

As the support-staging model recognizes the changing roles and demands of carers of people with ID and dementia it can be useful in constructing research, defining family-based support services, and setting public policy. This proof of concept exploration of caregiving situations will enable us to determine whether a better understanding of situations in which caregivers find themselves and what may be their lived experiences can be more effective in providing needed aid.

Trends & Patterns Noted Family Information Needs Noted

An older couple seeking counsel and help with their adult son with Down syndrome exemplifies the situation of many older parent caregivers, who live with their offspring at home, see them mature, and are then vexed by the onset of symptoms of what seems like an idiopathic neuropathology and the uncertainty as to what will happen next. Within the staging model, the parents can be identified as **conventional primary caregivers**, with concerns about what they are facing (objective and subjective need expression). Given the lack of clear causal determination of their son's behavior, they are in the **diagnostic phase**, uncertain of the reason for the behavioral change, as well as seeking help in dealing with their son's behavior – thus, also straddling the **explorative phase**.



References

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