

Understanding family caregiver's experiences with participant-directed programs

Providers, social workers, and other professionals must better understand families' subjective complexity and needs to provide more effective consumer driven programs. Participant Directed (PD) programs offer care recipients greater choice and control over the services and supports that they need to meet long-term care needs. Care recipients can choose who they want to provide care to them and can control their own budget. Overall, PD programs lead to lower unmet needs and higher levels of satisfaction. However, caregivers still experience unmet needs in these programs due to complexity around unpredictability of care challenges and transitions.

Understanding the more difficult-to-quantify aspects of caregiving complexity is important in successfully designing supports and training that meet the unique challenges faced by individual caregivers and care recipients. Areas to consider include:

		<p>Understanding the context of and targeting the specific areas of complexity for the family, which may include unpredictable challenges, managing multiple moving parts of care, and negotiating system-level roadblocks.</p>
		<p>Paying attention before, during, and after transitions to the changing needs or challenges of families.</p>
		<p>Coping with uncertainty through advocacy & preventing isolation of the caregiver and family.</p>
		<p>Providing supportive support by ensuring services are easily available, matched with the families' self-identified needs, and adjusted for changing demands of care. Supportive support also helps people have flexibility when working with systems and gives families opportunities to connect with others in similar positions.</p>
		<p>Avoiding unsupportive support by recognizing gaps in support and resources offered that are a mismatch to the actual needs and goals of the caregiver.</p>
		<p>Minimizing systemic challenges experienced by the family that can cause stress and frustration, i.e. high support broker and employee turnover, working with various inflexible systems and agencies.</p>