

Summary of Themes from DDS State System of Care Plan FY23-FY25

Paying Parents Forums

- **Parents should be paid** with Medicaid funding to provide services to their adult children, but only if they want to – some individuals want to stay with their parents; caring for their children is a parent’s full-time job, so it makes sense to pay them if they are already providing the supports
- **Parents immigrating from other countries** have a difficult time accessing the services their children need; paying parents would help alleviate some of the struggle
- **Respite is essential** – lack of respite workers could add to stress as with home providers
- **Parents feel the financial strain** of the pandemic and inflation – supporting their adult children often comes with costs not covered by Medicaid; financial stability of the parents translates to overall stability for the person; not financially viable if parents lose income-based benefits.
- **Parents had to leave their job** because of not having staff
- **Parents know their children’s needs** better than anyone else
- **Parents should not be paid** – parents of children under the age of 18 should not be paid; parenting should not be a paid position
- **Aging parents** – paying parents ceases to be sustainable as parents age; Paying parents does not address the problem of what to do when the parents die
- Paying parents or paying peers could **alter natural support relationships**; Person’s circle of support can become smaller when paying parents – don’t want to limit child’s social circle
- **System of checks and balances** – increased oversight and rule enforcement; regular and unannounced visits; accountability; documentation; record keeping; hold responsible for ISA plans, program goals, outcomes; need safeguards to assure the child’s interests and needs are priority; conflict free case management
- **Ombudsman** – Third party to assure paying parents is what the individual wants; to monitor compliance; regular review and re-approval; regular check in with person; awareness of situations where parent may have conflict of interest (limit independence/growth of child because of financial incentives)
- **The rights of the individual should be primary** – parents should not be allowed to limit or restrict the person’s rights, such as the ability to have visitors, date, or live the life they want

- **Worry about abuse, fraud, neglect, exploitation** – unhealthy and unsafe relationships between parents and child. Parents, like other caregivers, don't always do what is best for their adult children. Not all parents can provide a loving and secure home. Child's wants and needs might be outside what the parent wants for their child.
- **Parents should be the caregiver of last resort** – Paying parents should be a short-term solution; Prefer a fix to the staffing shortage problem; Challenge for aging parents to continue to provide care so not a good solution; be aware of burn-out and over-protective parents
- **Succession plan** – have a plan for alternatively living arrangement
- **Peer supports** to assure person's voice is heard
- **Family Focused case managers** to work with families who are paid
- **Paid parent should not be the guardian** – use public or an alternative private guardian
- **Independent rep payee** to limit financial exploitation/accounting of funds
- **Parents need support/networks** to not be isolated
- **Paid parents must follow the same rules and regulations** as shared living providers (e.g., background checks, training, home visits, DA oversight, behavior, home inspection, Health and Safety Guidelines, Behavior Support Guidelines)
- **Alternative options for paying parents:** Instead of paying parents, compensate parents for loss of income and disability-related costs (e.g., medical expense, additional services); just supplemental – not in exchange for services; have a contractual agreement with a tax-free stipend (like SLP)
- **A paid parent may not be what their adult child wants**
- **Shared Decision Making**
- **Workforce shortage** and difficulty finding staff with skills or training has left parents with no other choice than to provide the support themselves
- **Peers should also be paid** to provide support
- **Parent ambassadors**
- **Adopt models allowed in other states**
- **Children with complex needs/medical/behavioral**—often it is parent who is only person who can provide these special need supports
- **Some individuals do not want their parents to be their staff person** – would rather have different person support them

- **Pay parents when they need to step in** and cover when agency doesn't have staff; **Money goes away if not spent** – parents need to justify why funding is still needed when there are no workers to hire. Records don't show the unpaid coverage by family members who fill in and give the impression there is less need or need is being met
- **Pay for accommodations/accessibility needs**
- Concern that paying parents could **hinder development of alternative supported housing options**