The Person Nobody Programmes For: Caregivers of Persons with Severe Disabilities in Odisha

She wakes before 5 AM. She helps her son — 24 years old, with severe cerebral palsy — with his morning hygiene. She prepares his food, managing the texture and consistency that his swallowing difficulty requires. She attends to him throughout the morning, sometimes through the af...

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She has not had a full day away from her son in twenty-four years.

She does not appear in any welfare scheme as a "beneficiary" in her own name. Her son does — or should, if the documentation is in order — under the Rights of Persons with Disabilities Act 2016 and the Unique Disability Identity Card system. The Odisha government's Madhu Babu Pension Yojana sends Rs 500 per month to his account. Ayushman Bharat covers hospitalisation costs for the household. These benefits are real, and she navigated the paperwork to get them.

But she — the person whose labour makes all of these benefits functional, the person whose continuous physical and emotional effort is the only reason her son can live in a family rather than an institution — does not have her own welfare entitlement as a caregiver. There is no caregiver allowance in Indian policy. There is no caregiver health insurance. There is no caregiver respite programme that is systematically operational. She does not appear in MGNREGS records because she is not available to do MGNREGS work. She does not appear in the OUWSSB unorganised worker database because caregiving is not currently recognised as a registered occupational category. She does not appear in Mission Shakti SHG records because attending SHG meetings requires time she does not have.

She is invisible. And she is not alone.

The Scale of Invisible Caregiving in Odisha

There are no precise national or state-level statistics on the number of informal family caregivers for persons with severe disabilities in India. The disability data that does exist — the Census, the NSSO surveys, the UDID registration system — counts persons with disabilities, not the caregivers who support them.

What can be estimated: The Registrar General of India's 2011 Census recorded approximately 2.21 percent of the Indian population as having a disability. Odisha's population of approximately 4.2 crore would therefore include roughly 92 lakh persons with some form of disability. The RPwD Act 2016 defines "benchmark disability" as disability of 40 percent or more, and "high support need" as persons with benchmark disability who need high support from a caregiver. This high-support-need population — persons with severe intellectual disabilities, multiple disabilities, severe cerebral palsy, severe autism, acquired brain injury, or advanced neurodegenerative conditions — represents a fraction of the total disability count but constitutes the core population whose families carry the heaviest caregiving burden.

In rural Odisha, where institutional alternatives to family care are essentially absent, the assumption built into the welfare system is that the family will provide care. This assumption is accurate as a description of what happens. It is a failure as a welfare design principle — because it converts an involuntary, economically costly, physically and mentally demanding activity into something that is both taken for granted and unsupported.

The caregiver in this system is almost always a woman. India's gender division of care work is well-documented: daughters, daughters-in-law, mothers, and sisters bear the overwhelming majority of disability caregiving. A woman who is a primary caregiver for a family member with severe disability is effectively excluded from formal employment, from most welfare programme participation that requires regular attendance, and from the social and community engagement that constitutes the fabric of rural life. Her own health, her own income security, her own development — all are subordinated to the care role, with no systemic acknowledgment that this subordination has a cost.

The Policy Framework: What Exists (and What It Misses)

Rights of Persons with Disabilities Act, 2016

The RPwD Act is the foundational legal framework for disability welfare in India, covering 21 disability categories. It provides for:

- Reservation in government employment (4% for benchmark disability)
- Accessible infrastructure mandates
- Education inclusion provisions
- Social security schemes
- Certificate-based entitlements through UDID

The RPwD Act contains a provision on "caregiver support" in principle — it acknowledges that persons with high support needs require caregivers and that the state should support both the person with disability and the caregiver. In practice, the caregiver support provisions have not been operationalised into concrete entitlements at the national or state level. There is no national caregiver allowance. There is no national respite care programme. The acknowledgment is in the text; the implementation is absent.

UDID (Unique Disability Identity Card)

The UDID is the gateway to disability benefits. Issued by the District Medical Board, it certifies disability type and percentage, establishing benchmark disability status. For persons with high support needs, the UDID certificate should reflect the high-support requirement.

Problems with UDID access in Odisha:

- District Medical Board (DMB) is at the district headquarters. For a family in a remote tribal district whose member has severe disability, the journey to the DMB — with the person with disability — is physically and logistically very difficult.
- The DMB assessment process requires the presence of the person with disability. For persons with severe mobility impairment, this means transport arrangements that many rural families cannot manage.
- Reassessment requirements for UDID renewal create periodic access barriers.
- Many families in rural Odisha, particularly in tribal areas, are simply unaware that UDID exists. Their family member with severe disability has no documentation and therefore no access to any entitlement.

Madhu Babu Pension Yojana (MBPY) — Odisha

Odisha's state social security pension for persons with disabilities above 40 percent disability is Rs 500 per month. This pension goes to the person with disability, not to the caregiver. It is a meaningful supplementary income for disability households; it is not designed as caregiver support.

National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities

The National Trust Act 1999 established a statutory body (National Trust) to support persons with autism, cerebral palsy, intellectual disability, and multiple disabilities — the four categories with the highest support needs. The National Trust operates several schemes:

- **SAMARTH:** Day care centres and home-based care — this is the scheme most directly relevant to caregiver support, providing institutional or centre-based daytime care that gives caregivers a respite window.
- **GHARAUNDA:** Group homes for adults with intellectual and developmental disabilities who cannot live with families.
- **NIRAMAYA:** Health insurance scheme for persons with autism, cerebral palsy,

intellectual disability, and multiple disabilities (including those not covered by PMJAY).

- **PRERNA:** Caregiver training programme — online and offline training for family caregivers on disability management, communication techniques, pressure sore prevention, positioning, feeding, and behaviour management.

The National Trust schemes are theoretically accessible to families in Odisha. In practice, awareness is limited, the registration process requires the UDID, and the SAMARTH day care centres are predominantly urban — there are no functioning SAMARTH centres in most of Odisha's tribal districts.

PM-JANMAN and PVTG Disability Provisions

For PVTG communities in Odisha's tribal belt — where disability prevalence is often higher due to nutritional deficits, consanguineous marriage practices in isolated communities, and limited ante/postnatal care — PM-JANMAN includes health provisions that cover disability screening and referral. Implementation in PVTG habitations remains early-stage, but the policy framework creates an entry point for disability and caregiver support programming in the state's most remote communities.

The Mental Health of Caregivers

The international literature on informal caregiving is extensive and consistent: primary caregivers for persons with severe or permanent disability have substantially elevated rates of depression, anxiety, chronic pain, and burnout compared to non-caregivers. This is documented across contexts — caregivers of adults with dementia, caregivers of children with cerebral palsy, caregivers of persons with acquired brain injury.

In rural India, this mental health burden is compounded by:

Social isolation. Caregiving is isolating under any circumstance. In rural Odisha, where community life involves participation in festivals, agricultural activities, SHG meetings, and social gatherings, a caregiver who cannot leave the house is effectively removed from community life. This isolation accumulates into depression over months and years.

Financial stress. Disability households in low-income communities face higher-than-average healthcare costs (hospital visits, equipment, medication), supplemental nutrition costs, transport to specialist appointments, and the income forgone by the caregiver who cannot work. This financial stress is chronic and compounding.

Lack of acknowledgment. Perhaps the most psychologically damaging aspect of the invisible caregiver's situation is the absence of social acknowledgment. The care she provides is not seen as "work" by her community, by government systems, or by welfare programme design. She is simply a mother, a wife, a daughter-in-law, doing what is expected of her. The absence of acknowledgment — of anyone saying "what you do is significant, valuable, and deserving of support" — over years and decades produces a particular kind of erasure.

For NGOs working in disability and social justice, the caregiver's mental health is not a secondary concern. It is a primary programme component, because a caregiver who has collapsed — physically, mentally, or economically — cannot continue to provide care. The sustainability of family-based care for persons with severe disability depends on the caregiver's own wellbeing, and that dependency is not visible in welfare programme design.

Respite Care: The Missing Intervention

Respite care is the provision of temporary relief for caregivers — hours, a day, or longer periods during which trained care workers or volunteers take over the caregiving function, allowing the primary caregiver to rest, access health care, attend to personal affairs, or simply be alone.

In countries with developed disability welfare systems (UK's Carer's Allowance, Australia's Carer Gateway, Netherlands' respite care networks), respite care is a recognised and funded component of the disability support ecosystem. It is explicitly understood that supporting the caregiver is part of supporting the person with disability, because the care system collapses without the caregiver.

In India, respite care is mentioned in the RPwD Act and in National Trust programming. It is almost entirely absent in practice for rural caregivers. The SAMARTH day-care centres provide a form of respite during centre hours — but centres are urban, and the majority of Odisha's disability caregivers are rural.

An NGO programme that trains and deploys community-based respite care workers — similar in concept to the ASHA model, where community women are trained for a specific support function — could provide partial respite to caregivers in rural disability households. This is not a complex programme to design; it is a resource allocation question. The care function is not technically complex for many household-level tasks. What is needed is a trained person who comes, reliably, on a schedule that the caregiver can count on.

What NGOs Can Do: The Convergence Framework

UDID facilitation. The single highest-impact paperwork intervention for a family with a severely disabled member is getting the UDID processed. This requires accompanying the family to the District Medical Board, preparing the required documentation, navigating the application, following up on certificate issuance, and then using the UDID to access MBPY pension, NIRAMAYA health insurance, and National Trust scheme registration. This is a sequence of steps that requires an informed facilitator; most families cannot navigate it alone.

National Trust scheme registration. For families with members affected by autism, cerebral palsy, intellectual disability, or multiple disabilities, National Trust scheme registration (NIRAMAYA health insurance, PRERNA caregiver training, SAMARTH access where centres exist) is a consequential entitlement that very few rural families in Odisha are aware of.

Caregiver recognition and peer support groups. Forming caregiver support groups — regular, structured gatherings of caregivers who share their experiences, learn from each other, and receive training on care techniques — serves both the mental health function (acknowledgment, community, reduced isolation) and the practical function (peer skill-sharing on positioning, nutrition, communication). These groups can be convened monthly, facilitated by an NGO social worker, and over time can become self-sustaining peer networks.

MGNREGS accommodation advocacy. The RPwD Act does not explicitly carve out MGNREGS participation accommodations for caregivers of persons with severe disability. But there is scope — under the scheme's social inclusion provisions — for caregivers to be recognised as eligible for "proximity of worksite" provisions that allow them to work near their homes. Local advocacy with the Gram Panchayat and Block MGNREGS officer can sometimes produce work allocation arrangements that accommodate caregiver schedules.

CSR respite care pilot. A CSR-funded pilot of community-based respite care — where trained respite workers provide 8–12 hours per week of in-home care support for severely disabled persons — gives caregivers a predictable window of their own time. The cost per caregiver is modest; the impact on caregiver wellbeing is substantial.

For CSR Managers: Making the Invisible Visible

Caregiver support does not appear in any CSR thematic priority list because caregivers are not recognised as a population in Indian welfare taxonomy. They are embedded in the disability programme as an afterthought, in the women's empowerment programme as "women with constrained mobility," and in the health programme not at all.

The business case for CSR investment in caregiver support is fundamentally about sustainability: family-based care for persons with severe disability is the de facto Indian welfare system. It functions because women in these families have no alternative. The system does not compensate them, does not support them, does not protect them. When caregiver health collapses — and it does, over years of unsupported intensive caregiving — the person with disability enters the formal institutional system at enormous cost, or is left without care.

An investment in caregiver support — UDID facilitation, respite care, peer support groups, caregiver training — maintains the sustainability of the care arrangement that the welfare system depends on. It also acknowledges, for the first time in many caregivers' experience, that what they do has value and that they deserve support in doing it.

The metric framework for this space: number of UDIDs facilitated, number of National Trust registrations completed, number of caregiver peer groups active, number of respite care hours delivered, and caregiver wellbeing measured through validated instruments at programme start and 12 months later.

Schemes at a Glance

Scheme	Relevance	Nodal Department
RPwD Act 2016	Legal framework; caregiver support provisions	Social Justice & Empowerment
UDID	Disability certificate, gateway to all entitlements	District Medical Board / Social Justice
Madhu Babu Pension Yojana	Rs 500/month disability pension (Odisha)	Social Security Dept, Odisha
NIRAMAYA (National Trust)	Health insurance for autism/CP/ID/multiple disability	National Trust / Social Justice
SAMARTH (National Trust)	Day care / home-based care; limited rural reach	National Trust
PRERNA (National Trust)	Caregiver training programme (online/offline)	National Trust
GHARAUNDA (National Trust)	Group home for adults with intellectual/developmental disability	National Trust
Ayushman Bharat PMJAY	Hospitalisation coverage for eligible households	Health & Family Welfare
Mission Shakti SHGs	Peer group for caregiver women where schedule permits	Women & Child Development
PM-JANMAN	PVTG disability health screening and referral	Tribal Affairs Ministry

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What She Deserves

The woman who has been caring for her son for twenty-four years deserves the same recognition that a woman who has worked for twenty-four years in any other occupation would receive. She deserves income security, health coverage, rest, community, and the acknowledgment that what she has given — the decades of labour, the constant attention, the years of her own life that became entirely organised around another person's survival — is real work, of real value, that made a real difference.

The welfare system does not yet say this to her. Indian disability policy does not yet say this to her. In most of the districts of Odisha where she lives, no NGO is saying this to her either, because no NGO has the mandate or the budget to focus on the caregiver as the primary programme participant.

The first NGO that does — that makes the caregiver herself the subject of care, that builds a programme around her wellbeing as the foundation for everything else — will be doing something that is genuinely new in Odisha's social welfare landscape. And it will be building the most important investment in sustainable disability care that the state's welfare architecture has not yet made.

Sources: Rights of Persons with Disabilities Act 2016; National Trust Act 1999; National Trust scheme documentation (SAMARTH, NIRAMAYA, PRERNA, GHARAUNDA); Odisha Madhu Babu Pension Yojana guidelines; UDID portal documentation; Indian Journal of Medical Research — disability in tribal communities; PM-JANMAN scheme framework; NMHS (National Mental Health Survey) caregiver burden data; RPwD Act caregiver support provisions analysis (Disability Rights India Foundation).

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