M·POWER

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HUMAN RESOURCE DEVELOPMENT CENTRE

Summary Report

Supports and Services for Families of Young Children with Disabilities

Parents' Perspective

1. Introduction and Methodology

This Summary Report presents the main findings of a survey conducted under the Erasmus+ M-Power project, which focuses on strengthening family empowerment and resilience through shared learning between parents and professionals. The study explores parents' experiences with Early Childhood Intervention (ECI) services across countries with diverse social support systems. The report highlights emerging patterns and statistical trends to inform future project activities, learning resources, and policy recommendations.

The survey instruments were developed collaboratively by project partners through a literature review and analysis of existing practices. A comprehensive questionnaire consisting of 37 items was administered online based on voluntary informed consent. A parallel version was also deployed for professionals.

The questionnaire combined open-ended questions for qualitative insight with closed-ended questions using a three-point Likert scale ("Not at all", "To a small extent", and "To a large extent"). A total of 174 parents of children with disabilities (ChwD) participated from Bulgaria, Italy, the Netherlands, and Romania.

The survey explored five core thematic areas:

- [ ] Diagnosis, information, and referral pathways.
- [ ] Access to early childhood intervention and therapeutic services.
- [ ] Quality of professional support and family-centred practices.
- [ ] Parental emotional wellbeing, empowerment, and resilience.
- [ ] Unmet needs and recommendations for improving support services.

Quantitative data was analyzed using descriptive statistics, while open-ended responses underwent thematic analysis to capture qualitative experiences, recurring systemic challenges, and examples of effective family support.

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2. Participants

A total of 174 parents participated in the survey, with a relatively balanced distribution across the four partner countries: Bulgaria (42), Italy (43), the Netherlands (42) and Romania (47). Participants were recruited through the partner organisations and their service networks, providing valuable insights into the experiences of families accessing Early Childhood Intervention (ECI) services.

The children represented in the survey were predominantly boys (62%), while 38% were girls. Most children (86%) were currently receiving or had previously received ECI support. The average age at which support began was approximately 18 months, although this varied considerably depending on the child's needs and referral pathway. Centre-based services were the most common form of support (50%), followed by kindergarten or school-based services (21%) and home-based interventions (14%), while smaller numbers of families accessed services through hospitals, private practitioners or combined service models.

At the time of the survey, children were attending a range of educational settings, including special kindergartens or schools (37%), mainstream kindergartens (30%), primary or secondary schools (18%), specialised centres (7%) and nurseries (2%). Around 5% were not enrolled in an educational setting, primarily because of their young age.

The respondents were predominantly mothers (89% of those who answered this question), reflecting their primary caregiving role within participating families. The average caregiver age was 42 years,

while the average age of the children was 8 years.

Interpretation note: Participants were recruited through the partner organisations and their service networks. Therefore, the findings presented in this report reflect the experiences of the participating families and should be interpreted in the context of the participating sample rather than as nationally representative estimates of service provision.

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3. Survey Findings

The following sections present a thematic summary of the survey findings, highlighting the main patterns emerging from parents' experiences across the participating countries. The summaries integrate quantitative results with qualitative feedback where relevant, providing a concise overview of strengths, unmet needs and opportunities for strengthening family-centred early childhood intervention services for children with disabilities and their families.

3.1 Diagnosis, Information and Referral Pathways

Survey findings indicate that while initial diagnosis experiences are generally positive, subsequent support pathways remain highly uneven. Quantitative data reveals a critical split: only 38% to 49% of respondents experienced adequate support, while 31% to 42% received it to a small extent, and 16% to 29% received none at all.

Parents reported the highest satisfaction with the diagnostic process itself (49% to a large extent). However, post-diagnosis information is a major bottleneck; only 40% received clear guidance on subsequent steps, 42% received partial details, and 18% received none.

Referral mechanisms for Early Childhood Intervention (ECI) services (41% large extent, 28% none) and developmental screening (38% large extent, 29% none) remain critical gaps. Information on available therapies follows an identical pattern (40% large extent, 26% none).

Timeliness is also a severe systemic challenge, with 58% experiencing significant delays. Qualitative responses confirm that due to these administrative gaps, families routinely bypass official systems, relying on personal initiative, parent networks, or NGOs to secure vital speech, physical, and occupational therapies.

Key Takeaways: Initial diagnostic processes function relatively well, but post-diagnosis guidance and official referral pathways remain highly fragmented and delayed. Systemic frameworks must focus on bridging the gap between clinical diagnosis and immediate intervention services to prevent families from having to navigate care entirely on their own.

3.2. Service Enrolment and Professional Excellence

Families generally report positive experiences once they access early childhood intervention services, valuing the quality of service delivery over initial diagnosis and referral stages.

The enrolment process is a notable strength. Upon entering the program, 60% of parents received clear information about available services, 34% received partial details, and only 6% received none. This indicates highly effective initial communication once families are successfully engaged.

Professional competence emerged as the strongest result across the entire survey. A significant 69% of parents rated professionals as highly competent and effective communicators, 24% rated them so to a small extent, and only 7% not at all. This consistently positive assessment highlights the immense value of skilled, multidisciplinary staff in building institutional trust.

Key Takeaways: Active service provision functions exceptionally well, driven by high professional competence and effective communication once families are successfully engaged. The main opportunity for systemic improvement lies in sustaining this high standard of care by embedding professional excellence into wider, continuous support frameworks.

3.3 Parent Confidence and Cooperation with Professionals

Survey findings reveal that early childhood intervention services contribute positively to both parental confidence and professional collaboration, though peer support mechanisms remain a developmental area.

Cooperation with specialists and therapists emerged as a major systemic strength. A significant 68% of parents reported strong cooperation, 23% noted partial collaboration, and only 9% experienced none.

This effective partnership directly enhanced caregiving capacities: 52% of respondents felt more confident in the daily care of their child to a large extent. However, a notable portion faced gaps, with 28% experiencing only minor confidence gains and 21% reporting no improvement at all.

In contrast, formal and informal peer networking represents a weaker dimension. Connecting with other parents, support groups, or community networks produced highly mixed outcomes: only 40% succeeded to a large extent, 37% to a small extent, and 23% failed to establish any peer connections.

Key takeaways: Professional intervention is highly valued and effectively drives parental empowerment. To complement these professional successes, service networks should prioritize expanding institutional peer networks. Strengthening family-to-family connection channels will further enhance long-term family resilience and community-based wellbeing.

3.4 Resources, Affordability and Accessibility

Survey findings indicate that while physical accessibility and affordability are relative strengths, resource availability and organizational efficiency remain uneven across service systems.

Resource allocation shows a clear disparity. Resources intended to support parents represent a critical weakness, with only 39% receiving adequate support to a large extent, 35% partially, and 27% not at all. Resources for children scored slightly higher—with 46% receiving them to a large extent, 35% partially, and 19% not at all—meaning over half of the families faced resource deficits. Qualitative data confirms that many parents had to independently purchase equipment or rely on personal funds for assistive devices and materials.

Financial and geographical barriers present a more positive outlook. Affordability is a strength, with 54% finding services fully affordable, 27% partially, and 19% not at all. Similarly, 47% found services easily accessible in terms of distance, 36% partially, and 18% not at all. Service organization impacts timely access, with 45% rating it highly appropriate, 35% partially, and 19% not at all, indicating significant operational variances.

Key Takeaways: Physical and financial accessibility are relative strengths, but the actual availability of targeted resources for both parents and children remains insufficient. Systemic frameworks must move beyond basic availability to expand resource distribution and improve organizational efficiency to reduce waiting times.

3.5 Family Wellbeing, Emotional Support and Resilience

Survey findings underscore that while families deeply value empathetic engagement from professionals, dedicated emotional support and systemic stress mitigation for parents represent severe gaps in the entire study.

Professional empathy provides a foundational, yet inconsistent, baseline for family resilience. Regarding whether services were attuned to parents' emotional needs, results were highly mixed: 41% felt strongly supported, 33% partially, and 26% not at all. Qualitative data shows that parents deeply valued professionals who offered empathy and emotional reassurance alongside practical guidance, which directly helped reduce daily caregiving stress.

Direct institutional responses to parental stress emerged as a major systemic failure. Only 35% of parents felt their stress was addressed to a large extent, 27% partially, and a striking 39% experienced no stress-mitigation support at all—representing the highest negative response rate among related items.

The most critical deficit across the entire survey lies in the availability of dedicated psychological support. When seeking personal support—such as counselling, therapy, or emotional coping mechanisms—only 34% of parents received adequate assistance, 22% received partial help, and 44% received none at all.

Key takeaways: Current intervention systems heavily prioritize child-focused clinical needs while leaving structured psychological support for parents largely unavailable. To transition toward true family-centered early intervention, policies must urgently integrate institutional parent-targeted counselling and structured mental health resources. Addressing parental burnout is essential to sustain long-term family resilience and successful child developmental outcomes.

3.6 Family-Centred Practice and Continuity of Care

Survey findings indicate that while parents feel valued during stable care periods, experiences become volatile during transitions. Families consistently emphasize that true continuity depends on active involvement, clear communication, and coordinated guidance throughout the child's pathway.

Institutional transitions represent the most acute gaps in the entire study, though data reveals a trend of increasing support after families leave clinical settings:

- Hospital to Home: This is a major systemic deficit; only 19% of parents received strong support, 26% partial, and 55% received none at all.
- Home to Support Center: Guidance improves slightly but remains limited, with 32% experiencing strong support, 24% partial, and 44% receiving none.
- Support Center to Educational Services: Pathways into formal education are highly uneven, with 35% receiving strong support, 27% partial, and 38% facing a total lack of coordination.
- Exit from Services: Transitions out of the program remain critical, as only 49% of parents received clear information about future therapeutic options, 29% received partial data, and 23% received none.

In contrast, everyday collaboration within active services is a relative strength. Structured communication drives parental inclusion, with 43% of parents receiving clear information about their child's individual needs (34% partial, 23% none). Meaningful participation is a core highlight: 58% felt strongly included in the support team (26% partially, 16% excluded), and exactly 50% felt strongly involved in decisions regarding the Individual Support Plan (29% partially, 21% not at all). However, converting inclusion into practical navigation remains uneven; when seeking active organizational support to access external services, 40% received strong assistance, 29% partial, and 32% faced total gaps.

Key Takeaways: Family-centered intervention functions well during stable provision but falters significantly during structural shifts, causing parental stress. National frameworks must prioritize establishing standardized transition protocols—particularly from medical to community care—to ensure sustained, seamless support throughout the entire intervention pathway.

3.7 Support for Child Development and Family Focus

Survey findings indicate that early childhood intervention services provide meaningful support for many families by strengthening parents' knowledge and capacity to manage daily care. Approximately half of the respondents reported receiving substantial guidance across multiple practical dimensions, though a significant share of parents still received little or no support, highlighting uneven service delivery.

Practical guidance regarding specific developmental and behavioral areas yielded relatively consistent baselines:

- Child Development: 48% of parents received strong information and knowledge about their child's language, social, and cognitive development, while 35% received partial data, and 18% none.
- Communication and Play: Exactly 50% of respondents received strong support to communicate and engage in play or care calmly and effectively, whereas 26% reported partial support, and 24% faced total gaps.
- Behavior Management: 46% received strong support in managing their child's behavior, 31% received partial assistance, and 24% received none.

Qualitative responses reinforce these findings, as families consistently emphasize the immense value of practical, everyday advice over isolated therapy sessions. Increased knowledge directly enabled parents to feel more competent, established clearer daily routines, and strengthened their confidence in everyday caregiving.

In sharp contrast, a strictly family-centred approach emerged as a major structural weakness. When assessing whether the program was focused on the whole family rather than just the child, results were split almost evenly: 34% felt it was not at all family-focused, 33% felt it was only to a small extent, and 34% experienced it to a large extent. This strict three-way division indicates that while parents are operationally included in regular planning, many interventions continue to focus primarily on the child's immediate clinical milestones, while broader family priorities and environmental stressors receive less systematic attention.

Key Takeaways: Services excel at delivering practical child-focused guidance for communication, behavior, and development, which significantly boosts immediate parental confidence. However, intervention systems must actively transition from these child-centric clinical milestones toward holistic, family-centered frameworks that comprehensively address the structural needs of the entire family unit. [1]

3.8 Overall Impact of Services

Parents report that early childhood services yield substantial benefits for children's functional progress and parental caregiving competence, though the impact on reducing overall family stress remains modest.

Quantitative data reveals clear strengths in child-centered outcomes and functional development:

- Developmental Progress: A major highlight, with 57% of parents reporting strong improvements in communication, motor, and social skills (31% partial, 13% none).
- Social Participation: 52% observed a strong increase in the child's participation across home, preschool, and community settings (34% partial, 14% none).
- Independence: 49% noted strong improvements in the child's independence and social interactions (35% partial, 17% none).

The direct impact on the family unit shows a more balanced, yet restrained pattern:

- Parental Confidence: 49% experienced a strong increase in caregiving confidence, 31% partial, and 20% none.
- Family Daily Life: 40% felt a strong improvement in daily life, 39% partial, and 21% none.
- Parental Stress: This represents the weakest area of impact, with only 32% reporting a strong reduction in stress, 39% partial, and 29% experiencing no reduction at all.

These findings underscore that child-focused progress does not automatically mitigate family stress, reinforcing the need for interventions to simultaneously address the emotional demands placed on caregivers.

Key Takeaways: While services successfully drive developmental milestones and caregiver confidence, maximizing future impact requires transitioning away from isolated child interventions. National frameworks must prioritize comprehensive, well-coordinated family support models that seamlessly combine clinical therapies with sustained parental counseling and case management.

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4. Qualitative Insights from Parents' Open-Ended Responses

The open-ended responses complement the quantitative findings by providing a richer understanding of parents' lived experiences with early childhood intervention services. Across the participating countries, parents described remarkably similar experiences, highlighting both the benefits of early intervention and the challenges they encountered in accessing coordinated, family-centred support. Rather than presenting country-specific findings separately, this section synthesises the main themes emerging across all responses and illustrates them through parents' own words. These voices provide valuable context for the quantitative results presented in Section 3 and demonstrate the shared priorities and concerns of families across different national settings.

4.1 Types of Services Received After Birth or Diagnosis

Qualitative responses reveal that while the clinical composition of multidisciplinary care is relatively uniform, the structural delivery models are highly diverse.

When accessing support, parents most frequently reported receiving core therapeutic interventions, including developmental assessments, physiotherapy, speech and language therapy, occupational therapy, psychomotricity, and psychological support. Families expressed the highest appreciation for professionals who combined these clinical therapies with practical guidance that could be integrated directly into daily family life.

Institutional and Municipal Frameworks: A large portion of families rely on formal public health pathways, specialized hospital departments, child neurology clinics, and municipal or district support teams.

The Foundation and NGO Sector: Where state systems face capacity limits or rigid thresholds, families heavily depend on specialized foundations, non-governmental organizations (NGOs), and parent associations. These civil-society entries often prove crucial, offering holistic, family-centered programs and specialized interventions (such as play, music, or hydrotherapy) that bridge structural gaps in public infrastructure.

Ultimately, these open-ended responses demonstrate that while the demand for multidisciplinary intervention is universal, actual service availability remains fragmented, often shifting the burden of care coordination onto the families.

4.2 Structural Channels: How Parents Discover Services

The pathways through which families become aware of available interventions are deeply divided between formal institutional referrals and self-directed navigation.

Healthcare professionals—including general practitioners, pediatricians, child neurologists, specialized hospitals, and consultation offices—serve as primary formal entry points. In well-coordinated scenarios, these clinical experts act as direct conduits to social services, early intervention centers, and developmental screenings immediately following diagnosis.

Conversely, a substantial narrative across the qualitative feedback underscores that formal information pathways are frequently fragmented or non-existent. When official mechanisms fail, parents describe transitioning into a self-directed search model characterized by:

Informal Peer Networks: Relying heavily on recommendations from other parents, relatives, and parent-led support associations to identify trusted specialists.

Independent Digital Research: Utilizing internet searches, foundation networks, and NGO websites to locate available services and interpret complex funding opportunities.

These findings reinforce that families frequently face the overwhelming burden of "activating" services entirely on their own initiative. To prevent timely support from depending on a family's individual research capacity, current systems urgently require proactive, centralized information dissemination immediately at the point of medical diagnosis.

4.3 Material and Technical Resources Received

Qualitative insights show that while a diverse range of material and technical resources exists to support children’s integration, access to them is marked by significant systemic inequality and structural delays.

When support is successfully secured, parents report receiving crucial practical resources across several distinct categories:

Mobility and Specialized Equipment: Positioning and mobility aids, orthopedic footwear, orthotics, home adaptations, and medical or feeding devices.

Communication and Sensory Tools: Alternative and Augmentative Communication (AAC) technology, specific systems like PECS, and various educational or sensory materials.

Financial and Institutional Benefits: Disability pensions, municipal allowances, and partial reimbursements for specialized equipment like hearing aids.

Despite the high value parents place on these resources—particularly when paired with professional advice on integrating them into daily routines—the overall delivery remains highly inconsistent. A substantial portion of families across the sample reported receiving no material support at all. Many faced long administrative delays, while others described being forced to entirely self-fund or independently source essential equipment and therapeutic materials due to rigid public funding

thresholds. These inequalities underscore the urgent need for more equitable and proactive distribution systems for assistive technologies.

4.4 Effect of Services on Parents' and Family's Quality of Life

The overall impact of early childhood intervention services on family quality of life is deeply intertwined with how sustained and holistic the intervention path proves to be.

When services are continuous and comprehensive, families experience profound positive transformations. Parents consistently report feeling more competent, better informed, and less isolated. Effective professional partnerships empower caregivers with clear guidelines, improved behavior management techniques, and practical home-based routines. This enhanced knowledge directly reduces caregiver uncertainty, fosters smoother family dynamics, and significantly boosts the child's independence and social participation.

However, where services fail to maintain a family-centered approach, the impact on quality of life becomes highly fragmented. The qualitative data reveals two critical vulnerabilities:

The Post-Intake Gap: A notable group of parents describe feeling deeply welcomed during the initial intake phase, only to feel isolated or abandoned later due to interrupted help and insufficient individualization.

The Family Support Deficit: Many families report that when interventions focus exclusively on narrow clinical goals for the child while ignoring the parents' emotional needs, long waiting times and rigid service boundaries leave caregivers facing severe stress and burnout.

Ultimately, these parental experiences demonstrate that a child's developmental progress alone does not guarantee family wellbeing. To truly enhance long-term resilience, intervention frameworks must evolve beyond isolated child therapies, embedding sustained psychological counseling, parent training, and collaborative professional-family partnerships throughout the entire support journey.

4.5 Effect of Services on the Child's Quality of Life

Parents consistently observe profound, positive transformations in their children's development following participation in early childhood intervention services. While the pace of progress naturally varies depending on each child's individual needs and the complexity of their diagnosis, the overarching impact on daily participation remains substantial.

Qualitative insights highlight several core areas of child-centered improvement:

Communication Breakthroughs: Parents frequently report significant advancements in language acquisition, expression, and the "unlocking" of functional communication.

Autonomy and Daily Skills: Children demonstrate growing independence in everyday activities, marked by improved motor function, attention, and cognitive self-reliance.

Social and Emotional Growth: Caregivers note calmer behavior, enhanced emotional regulation, increased self-confidence, and a greater interest in interacting with family members and peers.

While a small minority of families experience slow or limited progress due to inconsistent service intensity, the qualitative feedback reflects a universal truth: early intervention fundamentally elevates a child's confidence, social inclusion, and long-term quality of life.

4.6 Clarity on Planning After Services

In sharp contrast to the developmental gains achieved during active intervention, long-term planning after the completion of services represents one of the weakest and most fragmented components of family support.

Parent experiences regarding future pathways are deeply divided into two distinct realities:

Structured Continuation: In well-coordinated scenarios, parents receive clear, therapist-guided recommendations for future specialist referrals, home practice frameworks, and smooth transitions into daycare or formal school settings.

Self-Mapped Pathways: Conversely, a significant portion of families face acute uncertainty once a specific program concludes. Parents routinely describe a total lack of transition planning, feeling forced to independently map out subsequent steps, source private providers, or navigate complex school placement systems while still awaiting proper clinical guidance.

These findings reinforce that developmental progress remains vulnerable without a guaranteed continuity of care. Families strongly emphasize that professional support should not end abruptly when a specific timeline finishes. National frameworks must prioritize mandatory, coordinated transition protocols and regular follow-ups adapted to the child's evolving developmental path.

4.7 Additional Support Received

Beyond formal early childhood intervention frameworks, families heavily rely on informal networks, civil society, and municipal mechanisms to sustain their resilience. These complementary sources of support play an essential role in strengthening parents' emotional wellbeing and reducing social isolation by directly filling structural gaps left by state services.

Qualitative insights identify three primary pillars of external assistance:

Extended Family and Peer Networks: Emotional encouragement and practical childcare support from grandparents, relatives, and parent groups provide vital, day-to-day relief.

Foundations and Community Initiatives: Non-governmental organizations, private providers, and parent associations offer crucial adaptive sports, family activities, moral counseling, and specialized motor therapies.

Municipal and Administrative Aid: Local funding mechanisms, financial guidance, and school-based accommodations help alleviate immediate systemic pressures.

While a portion of parents report receiving no outside assistance, the overwhelming consensus highlights that community-based and informal aid acts as a critical safety net when formal channels face administrative delays or rigid limits.

4.8 Additional Support Needed but Not Received

Despite their deep appreciation for the interventions available, parents consistently report profound, unmet systematic demands. These systemic deficiencies create significant barriers to long-term family wellbeing and highlight a clear disconnect between child-centric therapies and holistic family support.

Key outstanding needs articulated by caregivers include:

Dedicated Case Management: Parents overwhelmingly highlight the urgent need for a single, designated professional or case manager to coordinate logistics across health, education, and social care systems, removing the exhausting burden of independent navigation.

Caregiver Mental Health Infrastructure: Structured psychological counseling, parent training for behavior management, and formal peer support groups for parents remain critically underfunded or unavailable.

Service Capacity and Core Therapy Volume: Families routinely struggle with insufficient therapy hours (specifically for speech and behavioral interventions), a lack of take-home instructional materials, and a severe shortage of localized, close-to-home treatment options.

Financial and Logistical Relief: Clearer financial coverage, accessible respite care, after-school care options, and concrete help with complex municipal housing or budget schemes are frequently cited as unmet necessities.

Ultimately, these voices reinforce the central conclusion of this study. While active early intervention effectively drives child progress, current frameworks are not yet structured to sustain the family unit. Resolving these unmet needs requires transitioning toward continuous, well-financed, and genuinely family-centered systems of care.

Overall Reflection

The qualitative findings strongly reinforce the quantitative results, demonstrating that families face remarkably consistent experiences regardless of individual service settings or operational structures. While parents universally recognize the positive impact of early intervention on child development and caregiving confidence, they share identical, systemic challenges regarding care coordination, institutional transitions, access to centralized information, and parental psychological support.

These shared perspectives underline the critical importance of strengthening integrated, family-centred early childhood intervention systems. Future frameworks must balance immediate clinical goals for the child with proactive, sustained infrastructure that directly safeguards the emotional wellbeing and resilience of the entire family unit.

5. Overall Summary

5.1 Areas of Strength

- **Professional Competence:** Multidisciplinary staff expertise and effective communication stand out as the strongest survey assets.
- **Child Outcomes:** Services yield substantial, verified benefits in children's developmental milestones, autonomy, and social participation.
- **Collaboration and Inclusion:** Parents report strong operational cooperation and active involvement in shaping Individual Support Plans.
- **Financial Baseline:** Program affordability represents a relative operational strength across the sample.

5.2 Areas Needing Improvement

- **Caregiver Wellbeing:** Personal psychological counseling and mental health resources for parents represent the most critical deficit.

- **Stress Support:** Direct institutional responses to caregiver stress and emotional needs remain structurally weak.
- **Systemic Transitions:** Continuity of care during structural shifts is fragmented, particularly the move from hospital to home care.
- **Resource Disparity:** Practical assistance in navigating external networks and distributing parent-targeted materials remains uneven.
- **Holistic Service Design:** Interventions remain deeply split regarding family-centeredness, frequently overlooking broader household priorities.

5.3 Conclusion

Across the entire sample, intervention frameworks demonstrate a structural bias: they excel at child-focused developmental outcomes but systematically underperform in meeting the emotional, logistical, and psychological needs of parents.

While existing methodologies effectively promote child participation and bolster initial caregiving confidence, they mask persistent gaps in family-centered infrastructure. Emotional wellbeing, active stress management, transition coordination, and equitable resource allocation remain critical vulnerabilities. Transitioning toward a genuinely comprehensive, family-centered ecosystem is still incomplete. These empirical findings will directly guide the subsequent training phases of the M-Power project to build integrated, accessible, and family-responsive frameworks.

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