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Original Research Article

Outcomes in paediatric population diagnosed with birth intellectual disability: A non-interventional data collection study

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Abstract

Introduction: Neurodevelopmental diseases associated with intellectual disability affect cognitive functioning, which includes learning, problem solving, and judgement. Adaptive functioning includes everyday tasks including social interaction and communication skills.
Materials and Methods: This study compares demographic, development, function, healthcare utilization, and social outcomes in two groups of participants. Participants in Group-2 were older mean age = 9.81 years and indicates more physical growth, with higher mean values for weight, height, and BMI, than in Group-1 (mean age = 3.38 years). Gender composition was similar for both groups, with males being predominant.
Result: Developmental testing showed much greater scores in Group-2 for Developmental Quotient mean = 61.86 vs. 55.33, $p < 0.03078$ and Developmental Age in years mean = 5.25 vs. 1.73, $p < 0.00001$, with no significant differences for Developmental Age in months. Functional analysis identified Social Age in years was significantly higher in Group-2 mean = 5.58 vs. 2.42, $p < 0.00001$, but effects of Social Age in months and Social Quotient were insignificant. Both groups showed universal need for special education, but increased consumption of therapy services was detected in Group-1 57.81% vs. 17.18%.
Conclusion: Hospitalization and drug use were similar. Social outcome measures revealed comparable degrees of peer interaction, family support, and parental education, although Group-2 comprised more low socio-economic status (87.50% as opposed to 78.12%). The findings suggest that while Group-2 individuals are older and have superior developmental and functional outcomes, they experienced more socio-economic challenges and fewer therapeutic intervention accesses compared to Group-1.

Keywords: Socio-economic disparities, Therapy services utilization, Paediatric development, Healthcare access, Child health, Demographic comparison, Paediatric disability, Parental education, Medication usage, Physical growth parameters

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1. Introduction

Intellectual disability[1] involves neurodevelopmental disorders that have an impact on functioning in two domains: Cognitive functioning, like learning, problem solving and judgment. Adaptive functioning, daily living activities like communication abilities and participation in society. Furthermore, the adaptive and intellectual deficit starts early in the development phase, normally before age 18 years for diagnosis. Intellectual disability affects about 1% of the population, and of those about 85% have mild intellectual disability. In high-income countries, 2–3% of children have an intellectual disability. Intellectual disability is identified by significant limitations in both intellectual functioning and adaptive behaviour.

Intellectual functioning is measured with individually administered and psychometrically valid, comprehensive, culturally appropriate, psychometrically sound tests of

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intelligence. Although there is no longer a need to have a specific full-scale IQ test score to diagnose, standardized testing is employed in diagnosing the condition. A full-scale IQ score of approximately 70 to 75 represents a serious restriction in intellectual functioning.[2]

The IQ score must, however, be interpreted in relation to the individual's general difficulties with mental abilities. In addition, subtest scores may differ significantly such that the full-scale IQ score does not necessarily reflect general intellectual functioning. Thus, clinical discretion must be exercised in the interpretation of IQ test results.

Intellectual functioning includes the definition of intelligence, the skills measured by standardized intelligence tests, and the general agreement that intellectual functioning is affected by other dimensions of human functioning and by support systems.

Historically, intellectual or cognitive functioning has been tested using the intelligence quotient (IQ) tests, and it has been suggested to use an IQ of below 70 in making a clinical diagnosis of Intellectual Disability. Clinically, nowadays a score on two or more standard deviations below the population norm (around less than the 2nd/3rd percentile) on a standardized assessment of adaptive skills like the vineland adaptive behaviour scales is also used.

Adaptive behaviour is the set of idea, social, and practical skills learned and exhibited by individuals in their daily lives and include the following:

Three domains of adaptive functioning are viewed,[3]

1. Conceptual: language, reading, writing, mathematics, reasoning, knowledge, memory.
2. Social: empathy, social judgment, communication skills, ability to follow rules and ability to make and maintain friendships.
3. Practical: autonomy in the domains of personal care, work tasks, financial management, leisure, and planning school and work activities. Adaptive functioning is evaluated using standardized instruments with the person and interviews with others, e.g., family members, teachers and caregivers.

Age of onset is the third criterion for an ID diagnosis. This third criterion is necessary because it creates the age parameters for when ID begins or is first expressed. The criterion of age of onset "prior to the person reaching age 22" in the 12th edition of the AAIDD Manual relies on recent studies indicating that significant brain growth extends into our 20s. The clinical signs and symptoms of intellectual disability are initially identified in infancy and early childhood.

1.1. Background and rationale

Intellectual disability (ID) from birth is a chronic condition that can markedly influence developmental, cognitive, and functional outcomes in children. Gaining insight into actual outcomes using observational data is necessary for the planning of clinical assistance, education, and policy.

2. Aims and Objectives

2.1. Primary objective

To describe developmental, educational, social, and health outcomes in children diagnosed with birth intellectual disability.

2.2. Secondary objective

1. To determine common comorbidities (e.g., autism, epilepsy, motor disorders).
2. To assess utilization of healthcare, therapy, and educational support services.
3. To evaluate the factors associated with better or poorer outcomes (e.g., early intervention, family support, socioeconomic status)

3. Materials and Methods

3.1. Study design

A non-interventional, observational, cross sectional/ retrospective cohort study the New Drug Clinical Trail (NDCT) Rules 2019.[4,5] A single-center (e.g., hospitals, clinics, special education institutions).

3.2. Study population

Total Study Population of 128 Subjects of Age 0-5 yrs in Group A with 64 Subjects and Age Above 5 yrs in Group B with 64 Subjects

3.3. Inclusion criteria

In this study children with aged 0–18 years who are diagnosed with intellectual disability originating at or before birth (confirmed by medical/clinical records) and whose parental/guardian consent was obtained were included in the study.

3.4. Exclusion criteria

Acquired intellectual disability (e.g., from head trauma, infections after birth), Incomplete or inaccessible medical records and whose parents were consent were not obtained were excluded.

3.5. Data points

1. Demographics: Age, sex, socioeconomic status, parental education
2. Clinical Information: Cause of ID (e.g., genetic, hypoxic-ischemic encephalopathy), comorbidities

3. Developmental Outcomes: Milestone achievement, speech/language development
4. Functional Status: Self-care, mobility
5. Cognitive & Educational Outcomes: IQ scores, special education needs
6. Healthcare Utilization: Therapy (speech, OT, PT), hospitalizations, medications
7. Social Outcomes: Peer interactions, family support.[6-10]

3.6. Ethics and compliance

This study was done after taking Ethical approval from Institutional Review Board (IRB) and written amd informed consent has been taken from parents/guardians**,** Data anonymization and privacy protection in accordance with local regulations (e.g., GDPR, HIPAA) will be done.

4. **Results**

From **Table 1** data it was evident the demographic comparison between Group-1 and Group-2 reveals distinct differences across multiple parameters. Group-2 participants are significantly older, with a mean age of 9.81 years compared to 3.38 years in Group-1.

Correspondingly, Group-2 also shows higher mean values for height (1.24 vs. 0.98), weight (20.75 kg vs. 14.28 kg), and BMI (15.17 vs. 14.21), indicating greater overall physical development. Gender distribution is relatively similar across the two groups, with males forming the majority: 70.32% in Group-1 and 67.18% in Group-2. The standard deviations for weight and age are notably higher in Group-2, suggesting more variability in those parameters. Overall, Group-2 consists of older and physically larger individuals compared to Group-1, with no significant difference in gender composition.

Table 2 data show the analysis of developmental outcomes between Group-1 and Group-2 indicates significant differences in certain parameters. The Developmental Quotient Score is higher in Group-2 (mean = 61.86) compared to Group-1 (mean = 55.33), and the difference is statistically significant ($p < 0.03078$). Similarly, the Developmental Age Score in years is significantly greater in Group-2 (mean = 5.25 years) than in Group-1 (mean = 1.73 years), with a highly significant p-value of < 0.00001.

However, the Developmental Age Score in months shows a negligible difference between the groups (mean = 3.92 in Group-2 vs. 3.73 in Group-1), and this result is not statistically significant ($p < 0.82588$). These findings suggest that Group-2 has significantly better developmental outcomes in terms of quotient and age (in years), although the difference in developmental age measured in months is not meaningful.

From **Table 3** data it was evident the comparison of functional status between Group-1 and Group-2 reveals significant differences in some parameters. The Social Age (Years) is notably higher in Group-2 (mean = 5.58 years) compared to Group-1 (mean = 2.42 years), and this difference is statistically significant ($p < 0.00001$). However, the Social Age (Months) shows no statistically significant difference between the two groups ($p = 0.22628$), despite a slightly higher mean in Group-2 (6.00) than in Group-1 (2.00).

Similarly, the Social Quotient is marginally higher in Group-2 (mean = 2.44) than in Group-1 (mean = 1.15), but the difference is not statistically significant ($p = 0.38978$). These results suggest that Group-2 demonstrates significantly better functional status in terms of social age (in years), while other functional parameters show no meaningful statistical differences between the groups.[11,12]

From **Table 4** data it was evident the data on healthcare utilization shows distinct patterns between Group-1 and Group-2. All participants in both groups (100%) required special education services, indicating a universal need across the sample. However, a much higher proportion of Group-1 (57.81%) received therapy services (such as speech, occupational, or physical therapy) compared to only 17.18% in Group-2, highlighting a significant difference in therapeutic support.

Hospitalization rates were slightly higher in Group-1 (12.5%) compared to Group-2 (10.93%), though the difference is minimal. Medication usage was identical in both groups, with 10.93% of participants receiving medications. Overall, while both groups shared similar rates of hospitalizations and medication use, Group-1 had a notably higher utilization of therapy services.

From **Table 5** data it was evident the analysis of social outcomes shows strong similarities and a few differences between Group-1 and Group-2. Peer interactions were nearly universal in both groups, with 100% of Group-1 and 98.43% of Group-2 participants reported to have peer interactions. Family support and parental education were uniformly present in both groups (100% in each), indicating a consistent social environment.

In terms of socio-economic status, a higher proportion of participants in Group-2 (87.50%) fell into the "poor" category compared to Group-1 (78.12%), while Group-1 had a higher percentage of participants in the "standard" socio-economic group (21.88% vs. 12.50%). These findings highlight that although both groups benefit from strong family and educational support, Group-2 faces greater socio-economic disadvantage.

Table 1: Summary statistics of demographics

Parameter	Group-1			Group-2		
	Mean	Median	SD	Mean	Median	SD
Height	0.98	1.00	0.17	1.24	1.20	0.24
Weight	14.28	15.00	3.26	20.75	19.00	7.66
BMI	14.21	14.00	2.73	15.17	15.27	3.20
Gender	Male	45 (70.32%)		Male	43 (67.18%)	
	Female	19 (29.68%)		Female	21 (32.81%)	
Age	3.38	3.00	1.05	9.81	9.00	3.83

Table 2: Summary statistics of developmental outcomes

Parameter	Group-1			Group-2			P value
	Mean	Median	SD	Mean	Median	SD	
Developmental quotient score	55.33	55.50	14.28	61.86	59.50	15.64	<0.03078*
Developmental age score years	1.73	2.00	1.29	5.25	5.00	2.55	< 0.00001*
Developmental age score months	3.73	2.00	3.38	3.92	2.50	3.76	< 0.82588
* Significant at $p < 0.05$.							

Table 3: Summary statistics of functional status

Parameter	Group-1			Group-2			P value
	Mean	Median	SD	Mean	Median	SD	
Social age (years)	2.42	5.20	62.27	5.58	4.63	64.97	< 0.00001*
Social age (months)	2.00	5.50	63.00	6.00	4.00	63.50	0.22628
Social quotient	1.15	3.60	12.71	2.44	3.61	13.42	0.38978
* Significant at $p < 0.05$.							

Table 4: Summary statistics of healthcare utilization

Parameter	Group-1		Group-2	
	Yes	No	Yes	No
Special education needs	64 (100%)	0 (0%)	64 (100%)	0 (0%)
Therapy (speech, OT, PT)	37 (57.81%)	27 (42.18%)	11 (17.18%)	53 (82.81%)
Hospitalizations	8 (12.5%)	56 (87.5%)	7 (10.93%)	57 (89.06%)
Medications	7 (10.93%)	57 (89.06%)	7 (10.93%)	57 (89.06%)

Table 5: Summary statistics of social outcomes

Parameter	Group-1		Group-2	
	Yes	No	Yes	No
Peer interactions	64 (100%)	0 (0%)	63 (98.43%)	1 (1.57%)
Family support	64 (100%)	0 (0%)	64 (100%)	0 (0%)
Parental education	64 (100%)	0 (0%)	64 (100%)	0 (0%)
Parameter	Poor	Standard	Poor	Standard
Socio-economic status	50 (78.12%)	14 (21.88%)	56 (87.50%)	8 (12.50%)

5. Discussion

The demographic data revealed clear distinctions between Group-1 and Group-2 participants. Group-2 individuals were significantly older and exhibited greater physical development, as evidenced by higher mean height, weight, and BMI values. Despite these differences, gender distribution was similar across groups, with males comprising the majority in both. The increased variability in weight and age within Group-2 suggests a more heterogeneous sample in terms of physical growth. Developmental outcomes further highlighted significant differences between the groups. Group-2 demonstrated superior developmental performance, with higher Developmental Quotient Scores and Developmental Age Scores measured in years. Interestingly, when developmental age was assessed in months, no meaningful difference was observed. This suggests that while overall developmental progress was better in Group-2, finer monthly distinctions were less clear, potentially due to measurement sensitivity or age distribution differences.[13]

Functional status followed a comparable pattern, with Group-2 showing significantly higher Social Age measured in years, indicating better social development. However, no significant differences were detected in Social Age measured in months or in Social Quotient scores, reinforcing the notion that broader developmental markers better distinguish between groups than more granular monthly assessments.[14]

Healthcare utilization patterns highlighted distinct disparities in service use. Although all participants required special education services, Group-1 had a markedly higher engagement with therapeutic interventions, including speech, occupational, and physical therapy. Hospitalization and medication usage rates were similar between groups, suggesting comparable medical needs but differing levels of rehabilitative support.[15]

Lastly, social outcomes indicated that both groups benefit from strong family support and parental education, with near-universal peer interactions. However, Group-2 participants faced greater socio-economic challenges, as reflected by a higher proportion classified within the “poor” socio-economic status. This socio-economic disparity may influence the observed differences in developmental and functional outcomes, emphasizing the importance of considering environmental factors alongside individual characteristics.[14,15]

Overall, these findings underscore that Group-2 participants, despite being older and more physically developed, face socio-economic disadvantages but show better developmental and social functioning outcomes compared to Group-1. The variation in therapy utilization suggests potential differences in access or referral patterns, which warrant further exploration. Future research should examine the interplay between socio-economic status, healthcare utilization, and developmental trajectories to better tailor interventions for these populations.

6. Conclusion

This study demonstrates notable differences between Group-1 and Group-2 across demographic, developmental, functional, healthcare utilization, and social outcome measures. Group-2 participants were older and exhibited greater physical development, which corresponded with significantly higher developmental quotient and social age scores, reflecting better overall developmental and functional status. However, despite these positive developmental indicators, Group-2 faced greater socio-economic disadvantages, highlighting the complex interaction between biological maturity and environmental factors.

Both groups required special education support, underscoring universal educational needs. Interestingly, Group-1 engaged more extensively with therapeutic services such as speech, occupational, and physical therapy, suggesting differences in service access or referral that may affect developmental progress. Hospitalization and medication usage rates were similar across groups, indicating comparable health-related challenges. The near-universal family support and parental education levels in both groups suggest strong social foundations, yet socio-economic disparities, particularly in Group-2, may pose additional barriers to optimal development and access to resources. These findings emphasize the need for targeted interventions that address not only developmental delays but also the broader social determinants of health and education.

In summary, while Group-2’s older age and physical growth correspond with better developmental outcomes, socio-economic factors and healthcare utilization patterns remain critical influences. Future efforts should focus on ensuring equitable access to therapeutic services and addressing socio-economic barriers to support the developmental potential of all children.

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8. Ethics Statement

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10. Conflict of Interest

The author(s) do not have any conflict of interest

11. Data Availability Statement

The retrospective data collected from District early intervention center, Vijayawada.

12. Author Contributions

K. Gowtham Kumar: Conceptualization, Methodology, Design, Supervision.

K. Sivaji: Review, Writing & Editing.

T. Durga Prasad: Visualization, Resources

K. Joshua Daniel, K. Jessie, V. Veena Jessy: Data collection

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