Trajectories and Outcomes Among Children With Special Health Care Needs

Jon Quach, PhDab, Pauline W. Jansen, PhDc,d, Fiona K. Mensah, PhDab,e, Melissa Wake, MDb,e

abstract

BACKGROUND AND OBJECTIVE: Outcomes for children with special health care needs (SHCN) can vary by their patterns and persistence over time. We aimed to empirically establish typical SHCN trajectories throughout childhood and their predictive relationships with child and parent outcomes.

METHODS: The 2 cohorts of the nationally representative Longitudinal Study of Australian Children were recruited in 2004 at ages 0 to 1 (n = 5107, B cohort) and 4 to 5 years (n = 4983, K cohort). The parent-reported Children With SHCN Screener (Short Form) was completed at each of 4 biennial waves. Wave 4 outcomes were parent-reported behavior and health-related quality of life, teacher-reported learning, and directly assessed cognition. Both parents self-reported mental distress. We derived intracohort trajectories by using latent class analysis in Mplus. We compared mean outcome scores across trajectories by using linear regression, adjusting for socioeconomic position.

RESULTS: Four distinct SHCN trajectories were replicated in both cohorts: persistent (B 6.8%, K 8.7%), emerging (B 4.1%, K 11.5%), transient (B 7.9%, K 4.2%), and none (B 81.3%, K 75.6%). Every outcome was adversely affected except fathers’ mental health. From infancy to age 6 to 7 years, the persistent and emerging groups had similarly poor outcomes. From age 4 and 5 to 10 and 11 years, outcomes were incrementally poorer on moving from none to transient to emerging and to persistent SHCN. Effect sizes were largest for behavior, learning, and psychosocial outcomes.

CONCLUSIONS: Adverse outcomes are shaped more by cumulative burden than point prevalence of SHCNs. In addition to providing care according to a child’s need at any given time, prioritizing care toward persistent SHCNs may have the biggest benefits for children and parents.

WHAT’S KNOWN ON THIS SUBJECT: Children with special health care needs are a growing population in developed countries. They are at risk for poorer learning and behavioral outcomes, and their parents are more likely to have poorer mental health.

WHAT THIS STUDY ADDS: Four distinct and replicable special health care need profiles across 2 childhood epochs were categorized as none, transient, emerging, and persistent. The cumulative burden of special health care needs shaped adverse outcomes more than did point prevalence.

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Children with special health care needs (SHCN), defined as those who have chronic developmental, behavioral, emotional, and physical conditions and who need more support services than their peers,\textsuperscript{1,2} represent a growing population in developed countries.\textsuperscript{3,4} This definition captures a broad range of conditions that vary in complexity and comorbidities.\textsuperscript{5}

Much of the published knowledge about SHCN comes from large-scale cross-sectional surveys or studies that, although longitudinal, have measured SHCN at a single point in time. These studies consistently report poorer outcomes for children’s academic achievement, social relationships, and emotional engagement\textsuperscript{3,6,7} and also greater parental stress and mental health problems.\textsuperscript{8–10} Forrest et al\textsuperscript{6} reported that US children with SHCN in the fourth grade had poorer school attendance and learning outcomes in grade 6 than other children.

Yet children often have specific conditions with dynamic natural histories,\textsuperscript{11} such as later onsets or diagnosis, periods of recurrence, or even complete resolution.\textsuperscript{11,12} There is currently limited knowledge about the natural history and variability over time of SHCN as a broad grouping and about how outcomes may vary by differing trajectories (eg, emerging, persistent), if such exist.\textsuperscript{11} Newacheck et al\textsuperscript{13,14} and, more recently, Bethell et al\textsuperscript{15} have argued that this missing longitudinal information is crucial to inform the planning of medical, developmental, and education support services for these children across their life course.

In addressing this need, a number of possibilities arise. First, it is possible that cross-sectional population estimates overestimate and underestimate impacts of transitory and persistent SHCN, respectively. Second, the long-term outcomes could reflect when in the life course the SHCN were experienced, with maximal impacts not necessarily paralleling the timing of SHCN presence. Third, use of single-source outcomes precludes examining impacts in different contexts, such as at home and school, even though SHCNs could impose different limitations and differential impacts that are setting-specific. Fourth, these knowledge gaps are compounded by lack of information about the impacts of children’s SHCN on maternal and paternal outcomes, which may themselves engender policy and service needs.

We are able to empirically address these issues by using data from the first 4 biennial waves of the Longitudinal Study of Australian Children (LSAC), spanning 0 to 11 years of age. In 2 nationally representative Australian cohorts born 4 years apart, LSAC has repeatedly ascertained SHCNs every 2 years using the same measure, enabling a refined examination of SHCN trajectories across 4 waves spanning a 7-year period. Because it also provides multiple outcomes reported by mothers, fathers, and teachers, LSAC is ideal to examine the impacts of differing paths over time. Therefore, we aimed to determine the following:

1. Typical trajectories of SHCN in each cohort
2. Their predictive associations with
   a. Children’s outcomes both at home and at school, including cognition, learning, health-related quality of life, and behavior
   b. Mental health of both parents

METHODS

Study Design and Sample

Data were drawn from the first 4 waves of the nationally representative LSAC. Detailed information on the study design and sample is described elsewhere.\textsuperscript{16}

LSAC used a 2-stage cluster sampling design to create 2 independent cohorts, the birth (B) and preschool (K) cohorts. Both cohorts were concurrently enrolled in 2004 from the same geographic postcodes but were sampled independently. In the first stage, Australian postcodes were sampled after being stratified by state and urban versus rural status to ensure proportional geographic representation. Within each postcode, children registered on the Australian Medicare database (which includes 98% of all children) were randomly selected to participate. Follow-up waves have occurred biennially.

This study uses data from both cohorts, with the flow of participants shown in Fig 1. The B cohort spans the infant to early school years; 5107 children aged 0 to 1 years were enrolled in 2004 (Wave 1), of whom 4242 (83%) remained in the study in 2010 (Wave 4) when aged 6 to 7 years. The K cohort spans the preschool to elementary school years; 4983 children aged 4 to 5 years were enrolled in 2004 (Wave 1), of whom 4103 (82%) remained in the study at Wave 4 when aged 10 to 11 years. Retention was marginally lower for children with less highly educated parents and from non–English-speaking backgrounds.\textsuperscript{17}

The study was approved by the Australian Institute of Family Studies Ethics Committee, and parents provided written informed consent.

Procedures

At each data collection wave, trained researchers administered a face-to-face interview with the primary caregiver (usually the mother) in the family home, during which parents reported the SHCN measure. Children underwent direct assessments during the home visits, and their teachers completed a mailed survey. Secondary caregivers and parents living elsewhere, usually because of separation or divorce, self-completed surveys that were returned by mail.
Measures

Exposure (Special Health Care Needs Status at All Waves)

Exposure was defined according to the 2-item short form of the parent-reported Children With Special Health Care Needs Screener. The 2 items were “Does [child] currently need or use medicine prescribed by a doctor, other than vitamins?” and “Does [child] need or use more medical care than is usual for most children of the same age?” For each item, parents who responded “Yes” were asked 2 additional follow-up items as to whether the medication or service use was because of any medical, behavioral, or other health condition and, if so, whether the condition was expected to last >12 months. Children whose parent answered “yes” to all 3 parts of either item were classified as having an SHCN. The 2-item version has 80% to 90% agreement with the full 5-item version, with children with mainly functional limitations (eg, low vision or hearing) less reliably identified. We excluded children with missing SHCN information in all waves (N = 5 for B cohort, N = 6 for K cohort).

Outcomes

Table 1 details the outcome measures, which are predominantly from the Wave 4 follow-up, when the B cohort children were aged 6 to 7 years and the K cohort 10 to 11 years. They include teacher-reported child learning and behavior, parent-reported child behavior and health-related quality of life, mother and father self-reported mental distress, and directly assessed markers of children’s nonverbal cognition, measured by matrix reasoning, and verbal cognition, measured by receptive vocabulary. The K cohort marker of verbal cognition was collected at Wave 3 (age 8–9 years), the final wave in which this measure was collected.

Statistical Analysis

We used survey methods in all analyses to account for the unequal probability of participant selection into the sample and sample attrition and the multistage, clustered sampling design. Children were grouped based on repeatedly measured SHCN from Wave 1 to 4. The number of trajectories classified was determined on the basis of the minimum Bayesian information criterion and a significant Lo-Mendell-Rubin likelihood ratio test. This technique estimates the number of groups that best represent the data and indicates whether extracting additional groups would significantly improve model fit. Estimation was by maximum likelihood, with robust standard errors taking account of missing data by inference on the basis of available measures.

We then used these trajectories and Stata version 13.0 (Stata Corp, College Station, TX) to address Aim 2. We first examined the proportion of children from each derived SHCN trajectory according to Wave 1 family socioeconomic position (SEP) quintile, a composite LSAC measure derived from standardized scores for combined annual household income, parents’ years of education, and parents’ occupations.
TABLE 1  Outcome Measures at Wave 4 for Both B and K-Cohorts

<table>
<thead>
<tr>
<th>Measurea</th>
<th>Domain</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child assessment</td>
<td>WISC Matrices</td>
<td>Nonverbal cognition</td>
</tr>
<tr>
<td>Teacher reported Academic Rating Scale</td>
<td>PPVT</td>
<td>Verbal cognition</td>
</tr>
<tr>
<td>Approach to Learning</td>
<td>Strengths and Difficulties</td>
<td>Classroom behavior</td>
</tr>
<tr>
<td></td>
<td>Parent reported PedQL</td>
<td>Health-related quality of life</td>
</tr>
<tr>
<td></td>
<td>Strengths and Difficulties</td>
<td>Behavior</td>
</tr>
<tr>
<td>Parent self-report Kessler-6</td>
<td>Mother’s and father’s mental health</td>
<td>A 6-item, self-reported and validated measure of mental health distress, with higher scores indicating greater psychological distress.38 Scores are available for mothers and fathers.</td>
</tr>
</tbody>
</table>

All outcome scores were converted to z scores to enable differences between groups to be presented as effect sizes relative to the whole sample’s SD. We determined associations between the derived groups and outcomes by using unadjusted and adjusted linear regressions to estimate the mean differences between groups, with the no-SHCN group being the reference. Only adjusted regressions are presented because estimates attenuated only slightly when we included the a priori confounder SEP. Finally, we conducted a sensitivity analysis including current (Wave 4) SHCN as an additional term to determine whether the reported group differences were due solely to current SHCN as opposed to our derived trajectory groups.

RESULTS

Participant Demographics

Figure 1 shows the participant study flow, highlighting the high retention across the 4 waves, and Table 2 shows the demographic variables for each cohort. The cohorts had similar proportions of girls and boys (51.1% male for B cohort, 50.9% for K cohort), and most were in 2-parent families (90.6% and 87.3%, respectively), spoke English as the primary language at home (85.6% and 85.5%, respectively), and had a mother who had completed at least high school (68.3% and 62.0%, respectively).

SHCN Trajectories

Figure 2 shows the subgroups identified for each cohort. The 2 cohorts showed similar patterns of 4 distinct profiles spanning the 4 time points. Because latent class analysis is an empirical technique, we labeled the categories descriptively as no, transient, emerging, and persistent SHCN, recognizing that other terms (eg, chronic, new onset, and resolving) could have been selected instead. In the B cohort, spanning...
ages 0 to 1 years to 6 to 7 years, 6.8% of children were classified as persistent, 4.1% as emerging, 7.9% as transient, and 81.3% of children as having no SHCN. In the K cohort, spanning ages 4 to 5 years to 10 to 11 years, rates of SHCN were slightly higher, with 8.7% of children classified as persistent, 11.5% as emerging, 4.2% as transient, and 75.6% of children as having no SHCN.

Outcomes Associated With Trajectories

In the B cohort, the adjusted analyses demonstrate that the persistent and emerging groups had the poorest outcomes with similar effect sizes (Table 3). The largest effect sizes were for child psychosocial functioning (mean difference = −0.60; 95% confidence interval [CI], −0.75 to −0.44) and parent-reported child behavior difficulties (mean difference = 0.59; 95% CI, 0.44 to 0.74). Child verbal and nonverbal cognition at age 6 to 7 years were also markedly poorer for the persistent SHCN group.

In contrast, there were only small differences between the transient and no SHCN groups, with effect sizes ranging from 0.01 (95% CI, −0.17 to 0.16) for mothers’ mental health difficulties to 0.18 (95% CI, 0.01 to 0.35) for parent-reported child behavior difficulties. No evidence of impact of any of the SHCN trajectories was seen for fathers’ mental health.

For the K cohort, adjusted analyses demonstrated a clear gradient, with the best outcomes in the no-SHCN group and steadily poorer outcomes experienced across the transient, emerging, and persistent groups (all Ps < .001) (Table 4); effect sizes also tended to be larger for the K than the B cohort. The largest mean differences for the persistent group were for higher parent-reported child behavior difficulties (mean difference = 0.78; 95% CI, 0.62 to 0.93), teacher-reported child behavior difficulties (mean difference = 0.62; 95% CI, 0.45 to 0.78), and poorer psychosocial functioning (mean difference = −0.69; 95% CI, −0.82 to −0.55) and teacher-reported approach to learning (mean difference = −0.48; 95% CI, −0.63 to −0.32). For this age group, no differences in fathers’ mental health between the SHCN groups were evident.

In sensitivity analysis including current (Wave 4) SHCN in the
regression analyses, the reported mean differences between the SHCN trajectory groups in both cohorts only marginally attenuated (largest effect size change <0.05).

**DISCUSSION**

We found 4 distinct and replicable longitudinal SHCN profiles across 2 childhood developmental periods. For infants and preschoolers, we found that nearly half of SHCN are transient and that these children resemble those who never had an SHCN at 6 to 7 years; however, those with emerging and persistent SHCN had poorer outcomes with similarly substantial effect sizes. In older children, most SHCN are not transient, but when they are, children have poorer outcomes than those without any SHCN over this period. There is also a clear gradient in older children, with increasingly poorer outcomes from the no, to transient, to emerging, and finally persistent SHCN, which have by far the worst outcomes.

Our findings suggest that transient SHCN during the early years of school may have a more lasting effect than during the infant and preschool years. What we cannot determine from our

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**TABLE 3 Outcomes at Age 6–7 y Based on SHCN Subgroups From Age 0 for B Cohort**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Absolute Mean (SD)</th>
<th>z Score Mean Differences (95% CI) Compared With No-SHCN Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No SHCN</td>
<td>Transient</td>
</tr>
<tr>
<td>Cognition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Verbal</td>
<td>74.5 (5.1)</td>
<td>−0.02 (−0.17 to 0.13)</td>
</tr>
<tr>
<td>Nonverbal</td>
<td>10.8 (3.0)</td>
<td>0.02 (−0.15 to 0.19)</td>
</tr>
<tr>
<td>Academic Rating Scale</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maths</td>
<td>3.4 (0.8)</td>
<td>0.02 (−0.16 to 0.19)</td>
</tr>
<tr>
<td>Literacy</td>
<td>3.4 (0.8)</td>
<td>−0.01 (−0.19 to 0.17)</td>
</tr>
<tr>
<td>Approach to Learning</td>
<td>3.3 (0.7)</td>
<td>−0.15 (−0.33 to 0.06)</td>
</tr>
<tr>
<td>SDQ Total Difficulties</td>
<td>Parent</td>
<td>7.5 (4.6)</td>
</tr>
<tr>
<td></td>
<td>Teacher</td>
<td>5.8 (5.4)</td>
</tr>
<tr>
<td></td>
<td>Psychosocial</td>
<td>78.5 (12.6)</td>
</tr>
<tr>
<td></td>
<td>functioning</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Physical function</td>
<td>80.4 (17.7)</td>
</tr>
<tr>
<td>Parent mental health</td>
<td>Mother</td>
<td>3.0 (5.3)</td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>2.6 (2.8)</td>
</tr>
</tbody>
</table>

SDQ = Strengths and Difficulties Questionnaire.

*a* Adjusted for family SEP.

*b* Reference category.

*c* Trend analysis for outcomes in the direction of No, Transient, Emerging, and Persistent.

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**TABLE 4 Outcomes at Age 10–11 y Based on SHCN Subgroups From Age 4 for the K Cohort**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Absolute Mean (SD)</th>
<th>z Score Mean Differences (95% CI) Compared With No-SHCN Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No SHCN</td>
<td>Transient</td>
</tr>
<tr>
<td>Cognition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Verbal</td>
<td>78.5 (4.7)</td>
<td>−0.04 (−0.19 to 0.11)</td>
</tr>
<tr>
<td>Nonverbal</td>
<td>10.8 (2.9)</td>
<td>−0.06 (−0.21 to 0.09)</td>
</tr>
<tr>
<td>Academic Rating Scale</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maths</td>
<td>3.6 (0.8)</td>
<td>−0.20 (−0.38 to −0.01)</td>
</tr>
<tr>
<td>Literacy</td>
<td>3.9 (0.7)</td>
<td>−0.30 (−0.48 to −0.12)</td>
</tr>
<tr>
<td>Approach to Learning</td>
<td>3.4 (0.7)</td>
<td>−0.23 (−0.41 to −0.05)</td>
</tr>
<tr>
<td>SDQ Total Difficulties</td>
<td>Parent</td>
<td>7.1 (4.7)</td>
</tr>
<tr>
<td></td>
<td>Teacher</td>
<td>4.9 (5.1)</td>
</tr>
<tr>
<td></td>
<td>Psychosocial</td>
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<td></td>
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</tr>
<tr>
<td>Parent mental health</td>
<td>Mother</td>
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</tr>
<tr>
<td></td>
<td>Father</td>
<td>2.8 (3.0)</td>
</tr>
</tbody>
</table>

SDQ = Strengths and Difficulties Questionnaire.

*a* Adjusted for family SEP.

*b* Reference category, absolute scores from the measure.

*c* Trend analysis for outcomes in the direction of No, Transient, Emerging, and Persistent.
research is whether this difference reflects greater resilience to transient SHCN without treatment or greater receptivity to early interventions in very young children,\textsuperscript{23} which would enable them to catch up to their peers by school entry. For the older cohort, the duration of the SHCN before age 4 to 5 years is also unknown. Nonetheless, given that the majority of SHCN were transient and that these children did not have markedly poorer outcomes than those with no SHCN, long-term planning of care could potentially follow a period of watchful waiting after presenting concerns are appropriately addressed according to the type of SHCN.

In school-aged children, our findings build on previous research\textsuperscript{3,6–10} by demonstrating that the long-term impact on the child and family can be understood only in the context of the SHCN’s timing and persistence. Clearly, those delivering care to children with SHCN whose persistence can be predicted should plan for this care to be both prolonged and coordinated if their much poorer outcomes are to be mitigated. However, our findings suggest that even children with transient SHCN during the early years of school may need support beyond the resolution of their SHCN. In particular, the large effect sizes for child academic and mental health outcomes, 2 of the main achievements in middle childhood, support the importance of addressing and planning ongoing support for all children with SHCN during the early years of school.

Our study had several strengths. To our knowledge, it is the first to examine the natural history of child SHCN by repeated measurement every 2 years, spanning 4 data collection time points over 7 years for 2 independent cohorts that collectively span the full period of early and middle childhood. Our findings are immediately relevant to policy because the widely used and validated Children With Special Health Care Needs Screener is directly referable to SHCN definitions used by the US Maternal and Child Health Bureau and the Department of Health and Human Services.\textsuperscript{2} Second, our nationally representative sampling frame, large sample size, and high retention rate support both generalizability and internal validity, and they facilitate precise estimates of the associated outcomes for children in each of our SHCN groups. Finally, we are not aware of any studies that have examined the natural history of SHCN with such a wide range of child and parent outcomes, using validated measures and multiple informants as well as direct assessment.

With regard to limitations, our findings are not condition specific even though different conditions may dictate different trajectories. However, the broad-based definition is similar to those used by policymakers to target funding for children with SHCN, with scope for health and education professionals to individualize for each child’s needs. Second, we used the abbreviated Children With Special Health Care Needs Screener, which less precisely captures data on children with purely functioning-based health needs, such as vision and hearing loss.\textsuperscript{10} Given the impacts and permanence of such conditions,\textsuperscript{5,7} we may have underestimated the true impacts of persistent SHCN. However, because these children typically need additional medical care or medications, we believe that most would have been identified by the short form. Third, some missing exposure data may have affected the reported associations. However, sensitivity analyses did not show any significant differences in outcomes between children with and without SHCN data.

Outcomes were poorer not only in the health but the learning sphere. This raises the importance of appropriate care across the health and education sectors, which is a stated responsibility of the medical home paradigm.\textsuperscript{24} Our findings also point to providing care using a life course approach,\textsuperscript{15,25} given that child and parent outcomes vary according to long-term SHCN profiles. One potential way to achieve this care is by implementing the overarching principles of the learning health care system.\textsuperscript{26} This model involves continued evaluation of a child’s needs through active information sharing between health professionals (vertical integration) and other sectors, such as the child’s school (horizontal integration), to ensure that their needs are met from all sources of care. Although children with medical homes have fewer unmet needs,\textsuperscript{27} gaps in both health\textsuperscript{28} and education\textsuperscript{29} still exist and are associated with poorer outcomes.\textsuperscript{30,31}

Future research should examine whether certain conditions are more likely to be associated with different trajectories\textsuperscript{11,12} and, taking a life course approach, whether the timing or age at which SHCN are experienced also influence outcomes, over and above the pattern of the longitudinal profile. It will also be important to clarify the extent to which the risk and protective factors identified in conceptual models, such as those presented by O’Connor et al\textsuperscript{32} and Newacheck et al,\textsuperscript{13,14} explain differences in children’s outcomes based on their longitudinal SHCN profile. Understanding whether certain factors can be ameliorated and whether doing so leads to improved outcomes for these children will guide the planning of long-term medical, developmental, and education services for this growing population of children.

CONCLUSIONS
Distinct SHCN profiles during 2 important childhood periods, infant/ preschool and early school years, predict substantial variations in a broad range of important outcomes. Given that the most persistent SHCN
had the poorest outcomes in both groups, cumulative burden during childhood may play an important role in shaping adverse child and family outcomes. Those with persistent SHCN may need more preventive and therapeutic input throughout their life course to maximize their function and their own and their parents’ well-being.

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**COMPANION PAPER**: A companion to this article can be found on page e1040, online at www.pediatrics.org/cgi/doi/10.1542/peds.2015-0319.


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/content/135/4/e842.full.html