Parents’ and Service Providers’ Experiences of Accessing Health Services from an Intellectual Disability Health Team

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Abstract
A pediatric assessment service for children with Intellectual Disability (ID) was established in a culturally diverse region of Sydney, Australia, to meet the health needs of children and young people with ID. This paper reports on parents’ and providers’ experiences using qualitative and quantitative analysis of surveys. The survey responses from the parents’ enumerated their key concerns and the practical help they received from the service. Responses from service providers reported a high level of satisfaction with the service and valued the quality of assessment reports. The service facilitated inter-agency collaboration and enhanced the access to quality health care.

Keywords
adolescent, child, intellectual disability, experience

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Introduction
Children, young people and adults with Intellectual Disability (ID) often have negative experiences during interactions with the health services.¹,² A pediatric assessment service was established in 2012 to help improve the access to health care for children and adolescents with ID. This service commenced as a pilot project in South Western Region of Sydney in association with a tertiary level pediatric teaching hospital.³ It followed the principles of integrated services for chronic and complex healthcare needs.⁴ The service was located in a low socioeconomic Local Government Area (LGA) and catered to three most vulnerable LGAs as determined by the Social-Economic Indexes for Areas (SEIFA).⁵,⁶

Model of Care for Clinical Service delivery
A pediatric and youth clinic was run by a multidisciplinary team with pediatric doctors, nursing and other allied health support. Referrals to the clinic were made by health practitioners, disability service providers, schools or parents. The majority of referrals were related to behavioral issues, health-related concerns or inadequate disability supports. The health assessment and management plan were developed and a detailed health assessment report was provided to the family, the referring practitioner, and other relevant service providers.

In this paper, we report on findings from a survey of the experiences of families and providers, who had accessed direct ambulatory clinical care 5 years after the inception of the Service. The survey sought to determine, if the service has continued to achieve its objectives of addressing unmet health and/or social needs for children with ID. This process facilitated advocacy for ongoing funding of the program through the New South Wales (NSW), Ministry of Health.

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Methods

We collected both quantitative and qualitative data simultaneously from the questionnaire surveys of key stakeholders using a concurrent triangulation mixed methods approach. Ethics approval was obtained from the Quality Improvement Committee of the hospital. Survey forms were developed based on an earlier report, which was previously validated, for its utility to study the domains of patient satisfaction. The families interviewed in this second phase of service evaluation were different from the earlier survey, so the question of recall bias was nullified. All survey responses remained anonymous.

We used a purposeful strategy of selecting parents from our clinic cohort based on English versus non-English proficiency of families, level of intellectual disability (moderate vs profound), psychosocial stressors such as single parents versus intact families. We initially invited 23 parents to participate based on the above variables. Similarly, we invited 24 health professionals, to whom the service most frequently referred children for ongoing care, and 16 service providers who most commonly referred children to the service.

Survey of Parents and Carers

Parents/carers were asked about 5 domains that captured worries or concerns they had regarding their child (domain 1); their prior experience when accessing primary care practitioners or specialist healthcare providers (domain 2); any barriers they experienced when trying to get help for their child (domain 3), their interaction with the allied health disability providers (domain 4), and their experience and satisfaction with the service (domain 5).

Surveys of Specialist Service Providers

Two separate survey questionnaires were developed: one for whom the service referred for ongoing care and another for those who referred clients to the service). Questions enquired about their level of satisfaction with the referral process, and the quality of reports they received following the clinic assessments.

All surveys were designed using a 5-point Likert scale; 1—very dissatisfied to 5—very satisfied. Several direct questions were asked to both the parents and service providers with opportunities to share their experiences with free text responses. These responses provided the qualitative data for analysis, concurrently with the quantitative data obtained from the Likert scale responses.

Data analysis. Quantitative data were analyzed descriptively using Microsoft Excel, while qualitative data was analyzed using thematic analysis. In this approach, firstly we analyzed the quantitative data and triangulated the results with qualitative data resulting in mixing of both types of data at the stages of data analysis and results. Data collection and analysis was therefore done until no new themes emerged, and the results are presented in a mixed manner. The quantitative data is presented in the results as Mean (SD) scores, while quotes and general themes are presented from qualitative data analysis.

The manual coding of qualitative data was done using the framework of the patient satisfaction questions that were collected in the survey questionnaire. The “line by line coding” did not identify any new themes but supplemented and enhanced the trustworthiness of the qualitative data. We maintained rigor of the study findings by frequent discussion of the study findings in the team meetings and getting feedback by presenting the research findings to colleagues from other similar services.

Results

The Experience of Parents Attending the Clinic

Of 23 parents who were invited to participate, 13 (56.5%) completed the survey. The key parental concerns are highlighted in Table 1. These included: their child’s physical health, communication, and poor eating habits. The mean satisfaction ratings for the helpfulness of the clinic were very high (Table 2). The main barriers for access to health services included: lack of awareness of services, financial distress, and difficulties in travel due to their child’s behavior (Table 2). The clinic also helped the families to identify problems, led to self-reported reduction in parental stress, and provided advice, education and practical help to the families. Some of the free text comments from the parents that highlighted the help they received:

They helped my husband who was depressed. They have helped a lot over the years. We do not have much other support from family or friends. This clinic is the only support we have. (P1)

They provide me with answers to my questions and medical advice. Generally, they are very helpful with my concerns about my son and myself. I am very happy with the help I get. They are very supportive. (P2)

Five parents (5/13, 38.5%) reported that they had not taken their child/young person to any healthcare professional prior to coming to our service. Parents reported less satisfaction with their family doctor (mean rating for satisfaction 3.66 (SD = 1.51, n = 6), compared to a pediatrician, psychiatrist or psychologist (mean rating 4.0 (SD = 1.10, n = 6).

The satisfaction with disability service providers was variable, with therapy services such as speech therapy, having the highest rating (mean = 3.0, SD = 0.71, n = 5), while Community participation/respite had the lowest rating (mean = 1.66, SD = 0.58, n = 3).
Seven out of 16 (43.8%) referrers returned completed surveys (43.8%). Their responses indicated that they were generally satisfied with the referral process, with a mean rating on a 5-point Likert scale of 4.14 (SD = 1.07, n = 7). Comments conveyed that school staff greatly appreciated the opportunity to refer students to the clinic. Some respondents reported negative experiences such as long intake form and waiting times, their clinical role being diminished with the involvement of other services and there were communication gaps between services providers.

The referrers appreciated the reports of assessment (mean satisfaction rating of 4.57 (SD = 0.79, n = 7) that provided valuable evidence for schools in requesting additional resources, services and funding for these students.

Referrers reported that clinic activities helped them to upskill and identified several gaps in services for people with ID such as access to mental health services and psychiatrists, lack of disability service providers, interpreters, and sometimes lack of engagement of families with their service.

A total of 9 out of 24 (37.5%) surveys were returned by specialist providers, to whom the clinic referred patients for ongoing medical follow up. The respondents were very positive about the service and their interaction with service/clinic staff. They appreciated the detailed and relevant information that was provided.

Several benefits were reported for the children and their parents/carers as a result of the linkage between the clinic and the specialists. These included having a direct impact on child and hospital services. Some of these reported by respondents were advocacy and enhanced access to quality care for the children, enhanced access to immunization services, reduced parental stress, facilitation for surgical procedures for children with ID in hospital, reduced emergency and hospital presentations, and provision of information and supports for children with ID.

### Discussion

The results of this evaluation demonstrate that this model of care for providing comprehensive assessments by a team of professionals offers access to quality health care for children with ID. It was considered as a success by parents/carers and most health and non-health providers who interacted with the service. The results highlighted the ongoing positive experiences of the families and helped us to

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**Table 1. Parental Concerns about Their Child: Parent Responses (N=13).**

| Possible concerns                                | Level of worry/ concern<sup>a</sup> | Score | SD  | N  |
|-------------------------------------------------|------------------------------------|-------|-----|----|
| My child’s physical health                      |                                    | 3.23  | 1.42| 11 |
| My child not eating well                        |                                    | 2.46  | 1.13| 10 |
| Ensuring my child takes his/her medications     |                                    | 2.30  | 1.49| 6  |
| Managing my child’s special diet                |                                    | 1.75  | 0.96| 2  |
| My child is overweight                          |                                    | 2.62  | 1.56| 8  |
| My child is underweight                        |                                    | 1.80  | 1.30| 2  |
| My child’s behavior                             |                                    | 3.00  | 1.78| 8  |
| How my child communicates                       |                                    | 3.82  | 0.98| 11 |
| Sleep problems with my child                   |                                    | 2.46  | 1.56| 8  |
| My child seems to have pain or discomfort       |                                    | 2.23  | 1.30| 8  |
| My child’s sexual development                   |                                    | 2.33  | 1.66| 4  |
| For girls – menstrual problems                  |                                    | 3.33  | 2.08| 2  |
| Dental care for my child                        |                                    | 2.77  | 1.74| 8  |

N – Indicates the number of parents who identified this issue as relevant for them.

<sup>a</sup>Refers to overall level of concern, rated by parents on a 5-point Likert scale, from 1 to 5.

**Table 2. Helpfulness of the Clinic and Barriers in Addressing Health-Related Concerns: Parent Responses (N = 13).**

| Possible concerns/barriers                      | Level<sup>a</sup> | Score | SD  | N  |
|------------------------------------------------|-------------------|-------|-----|----|
| My child’s physical health                      |                   | 4.9   | 0.32| 10 |
| My child not eating well                        |                   | 4.75  | 0.5 | 4  |
| Ensuring my child takes his/her medications     |                   | 4.8   | 0.45| 5  |
| Managing my child’s special diet                |                   | 5     | 0   | 3  |
| My child is overweight                          |                   | 4.83  | 0.41| 6  |
| My child is underweight                        |                   | 0     | 0   | 0  |
| My child’s behavior                             |                   | 4.63  | 0.52| 8  |
| How my child communicates                       |                   | 4.67  | 0.5 | 9  |
| Sleep problems with my child                   |                   | 4.33  | 1.03| 6  |
| My child seems to have pain or discomfort       |                   | 4.6   | 0.89| 5  |
| My child’s sexual development                   |                   | 3.33  | 0.58| 3  |
| For girls – menstrual problems                  |                   | 4.33  | 0.58| 3  |
| Dental care for my child                        |                   | 5     | 0   | 7  |
| I don’t know where to get information           |                   | 2.39  | 1.33| 13 |
| I need help with physical aspects               |                   | 2.08  | 1.50| 13 |
| I don’t have enough money                       |                   | 3.23  | 0.93| 13 |
| I have difficulties getting transport           |                   | 1.62  | 0.87| 13 |
| I am not able to get my child into respite care |                   | 1.91  | 1.64| 11 |
| Appointment times are not always at a good time for me | | 2.08  | 1.19| 13 |
| My own health is not very good                  |                   | 2.15  | 1.07| 13 |
| My child’s behavior makes it difficult for me to take them anywhere | | 2.77  | 1.83| 13 |

N – Indicates the number of parents who identified this issue as relevant for them.

<sup>a</sup>Refers to overall level of helpfulness/difficulty, rated by parents on a 5-point Likert scale, from 1 to 5.
advocate for ongoing funding for the program from the New south Wales, state Ministry of Health.

The parents/carers expressed their appreciation of having access to the clinic and reported their experience as very positive. This program plugged a services gap in the mainstream health services that may not be able to make adjustments for people with ID.9

Parents’ perceptions that the specialists provided a more comprehensive assessment and treatment plan compared with family doctors in general practice may be due to lack of expertise and inability to accommodate the needs of people with ID.10,11

As reported in our study, access to quality disability services, respite services and a lack of trained staff are similar service problems which have been reported in another study.12 Furthermore, the families seen in our services have additional vulnerabilities such as being recent refugees with language barriers, who consequently have challenges in interacting with disability providers.13

Some services providers suggested a need for clarification over who has overriding responsibility for the child with ID. This reflects the challenges of integrated care that can arise when other services become involved in the care of a managing clinician.14,15

Specialist providers reported that they were very satisfied with the referral service and saw it as providing much needed advocacy and access. This is similar to the results obtained from the earlier evaluation and confirms the value of having a purpose-designed support service that work in partnership with mainstream services for people with ID.5

A range of disparities are considered to be experienced by people with ID, including a greater prevalence of adverse conditions; insufficient focus on health promotion, and inadequate access to quality health care services.16 Our specific ID health team provided a family-focused and equitable care that empowered caregivers and family members to adequately care for a child with ID in their care.

Although the response rate of the survey varied from 56.5% for parents, 43.8% for referrers and 37.5% for people who received the referrals from the service, most of the responses received from professionals were detailed and informative and provided useful qualitative data.

Conclusions

Both parents/carers and professionals who interacted with the ID health service appreciated the provision of such a service in the community. Parents reported that they valued not only the clinical component of the service but also the emotional and social support provided. Health care professionals consider the clinic enhanced the diagnosis and management of health problems. The provision of pathways of care for children to have procedures in hospital was viewed positively. In summary, the service has facilitated inter-agency coordination and collaboration and enhanced the access of these children to quality health care.

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Supplemental Material

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