

BACKGROUND

Children with complex medical conditions and co-morbidities are now surviving longer into adulthood. Approximately 11% of children aged 0-14 years have a disability, half of whom have impairment that limits daily activities (Simpson et al., 2016). Along with increased quality of life and survival rates, children with extreme conditions require increased care not only in hospital but also in the home, school and community environments.

Whilst much of this care delivery takes place in the patients' homes, children can spend significant periods of time in the hospital. Admissions to hospital, planned or acute, can be either close to or away from home, adding to the everyday difficulties of family life.

The objective of the project was to increase recognition of the numbers of CMC, identify services that are involved in their care and how these services are coordinated currently, and highlight whether inequities exist in care delivery. By being better informed, those professionals managing services have more scope to plan and coordinate care efficiently and effectively for CMC



METHODS

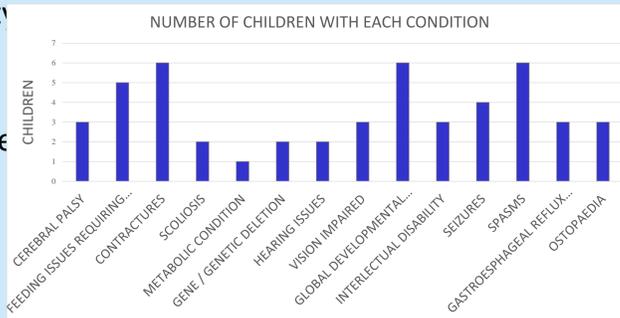
1. Criteria for patients to be audited were identified
2. A literature review determined existing Standards of Practice (NZ or international)
3. Audit tool developed.
4. Retrospective audit of six patients from one clinic who met criteria.
5. Lastly, two patients from the audit list were identified so that service mapping summaries could be developed to highlight the services involved in care delivery for these complex patients.

RESULTS

Prognosis; Sharing Significant News

The audit found that currently there is no consistent way of delivering a diagnosis/prognosis to the child and family within the DHB.

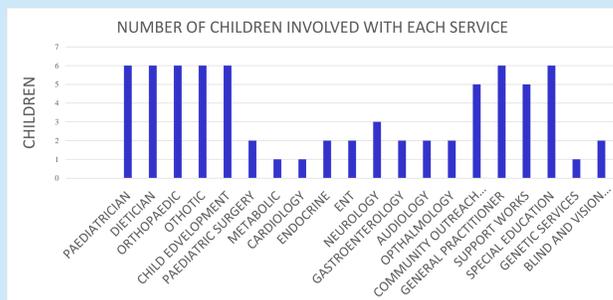
Figure 1 shows number of different diagnosis /conditions each child in the audited cohort has (average: 6 conditions).



Transfer and Liaison between Hospital and Community Services

It was difficult to determine from the audit whether an agreed transfer plan was given for the child before discharge, or following diagnosis, as no formal plans were found in the clinical notes.

Figure 2 shows children were involved with between three and ten services, with an average of six services.



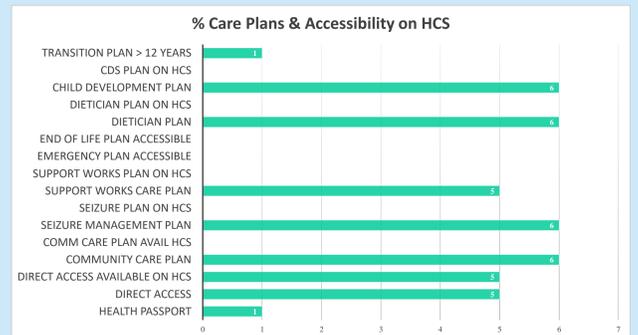
Multidisciplinary Assessment of Needs

All children were either under the care of Support Works or ACC and received an annual review of needs. All children and their families could also access a needs assessor if the situation changed between reviews. There was very little difference between the access to assessments between Support Works as the provider and ACC as the provider.

A Child and Family Care Plan

The needs of each child and family varied depending on the number of co-existing conditions each child had, therefore planning of care was very complex. Most children had multiple care plans.

Figure 3 demonstrates percentage of plans available and those accessible to all health professionals on Health Connect South (HCS).



An End of Life Plan

None of the children audited had an End of Life Plan, or any form of documented discussion regarding treatment during emergency situations.

Bereavement Support Services

Currently these services would be sought on an as needed basis. This would be a combined approach utilising the skills of the social worker, community nurse and CDS psychologist.

RECOMMENDATIONS

- A further 3-4 month project to develop the recommendations of this report District wide.
- Consumer focus groups to understand key local issues.
- Development of Standards of Practice (SOP) for service and care delivery for Children with Medical Complexity
- Health passport includes emergency management plans, end of life plans, life wishes plan and any complex safety plans
- A process for bereavement service provision is developed.
- CMC multidisciplinary clinics including a one stop shop for needs assessment needs.
- Business case for Clinical Nurse Specialists (CNS) in Nelson and Wairau regions to deliver care for CMC and assist families to navigate services.

REFERENCES:

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- Simpson, J., Wicken, A., Gallagher, S., Adams, J., Duncanson, M., Oben, G., & Morris, S. (2017). The Health of Children and Young People with Chronic Conditions and Disabilities in the South Island 2016. New Zealand Child and Youth Epidemiology Service.
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