

Multidisciplinary Pilot Service for Children with ID: Evaluation Survey of Parents and Carers

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Background

- Children and adolescents with intellectual disabilities (ID) often have unmet complex health needs
- Their parents/carers often experience barriers to locating and accessing services to assist in diagnosing/managing those needs
- In disadvantaged populations, other factors impact on the ability of parents of children with ID, to have the child's needs met



Pilot Paediatric Assessment Clinic



- The PAC was set up in 2012 under the auspices of the CHW
- Funding provided by the NSW state government (MOH)
- Target community is living in a lower socio-economic and culturally diverse metropolitan region



Pilot Service Structure



- A multidisciplinary team was established consisting of a paediatrician, paediatric registrar, CNC and social worker. An exercise physiologist and dietitian were subsequently added to the team.

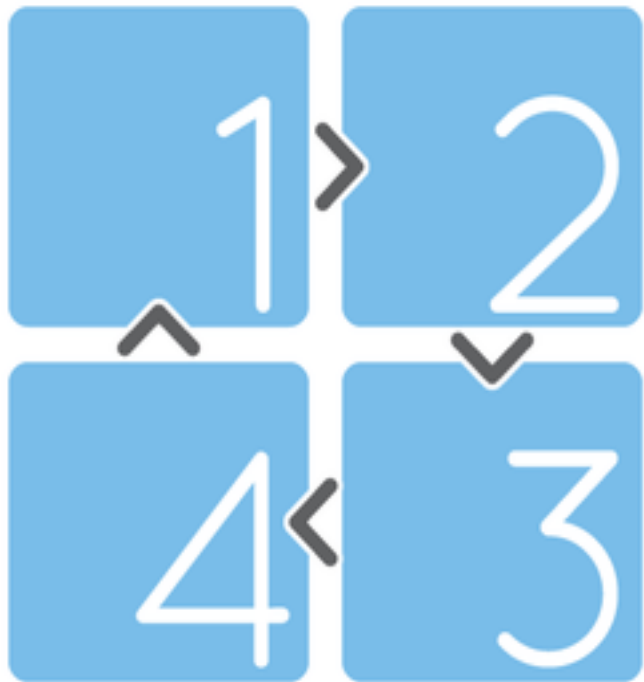


Aims of the Service

- To enhance access to specialist health care for children aged 6-18 years with ID and complex health needs
- To provide specialist services, develop new clinical pathways, and help build the capacity of mainstream service providers to meet the health needs of children with ID



Referral and Assessment Process of the Clinic



- Step 1: preliminary telephone consultation with the parent – CNC and social worker. An interpreter will join, if needed
- Step 2: parent/carer and other family members involved in care of the child are interviewed without the child. Paediatrician, CNC and social worker attend



Referral and Assessment Process of the Clinic



- Step 3: Paediatrician, CNC and social worker attend this meeting with the parent/carer and child. A medical and developmental assessment is performed.
- Step 4: The team reviews the identified issues and develops a provisional management plan to discuss with the family at a further meeting.



Assessment of Parent/ Carer Satisfaction: Method

- Completion of a survey by the parent/carer in a face to face session with the team's project officer
- Parents/carers who had completed their second visit to the clinic between 1 May and 30 Oct 2017 were invited to participate
- All responses were de-identified
- For those who were not proficient in English (n=2), an interpreter also attended the meeting



The Survey Form

- Parents could respond to a list of 13 possible “worries or concerns” about their child’s health/development. Asked to rate concerns on a 5-point Likert scale (1 = not at all worried; 5 = extremely worried)
- Asked to indicate how helpful the clinic visit had been that day in addressing “worries or concerns”. Asked to respond using a 5-point Likert scale (1 = not at all helpful; 5 = very helpful)



The Survey Form cont.

- Also asked about their experience of communication with the team during the clinic visit. Asked to respond to 13 statements about communication using a 5-point Likert scale (1 = strongly disagree; 5 = strongly agree)
- Asked to rate their overall satisfaction with clinic visits (1 = very dissatisfied; 5 = very satisfied)
- Also asked to indicate how important they felt it was for different team members to attend the clinic



Table 1. Worries or concerns about their child: parent reports (N = 13)

Possible worries or concerns	Level of worry/concern		
	X	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 behaviour	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



Table 2. Helpfulness of the clinic in addressing health-related concerns: parent responses (N = 13)

Level of helpfulness			
Possible worries or concerns	X	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 behaviour	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



Table 3. Desirable communication outcomes: parent responses (N = 13)

Desirable outcomes	Level of agreement		
	X	SD	N
The staff made me feel comfortable	5	0	13
I felt I could talk openly with the staff	5	0	13
I have a better understanding of how help can be obtained	4.69	0.63	13
I feel more supported and understood	4.85	0.38	13
The way the staff spoke to me was easy to understand	5	0	13
The staff focussed on issues that were concerning me	5	0	13
There was enough time to discuss the things I needed to talk about	4.92	0.28	13
I felt my opinion was respected	5	0	13
The staff were interested in improving my child's health and wellbeing	4.92	0.28	13
I have a clearer understanding of my child's health issues	4.75	0.45	12
I received some helpful information	4.92	0.28	13



Table 4. Importance of attendance of health care staff at the clinic: parent responses (N = 13)

	Essential	Useful	Unsure
Paediatrician	***** **	*	
Adult Physician (registrar)	*****	***	**
Psychiatrist	***		
Therapists/Allied Health	*****	**	
Case Manager or other disability support worker		*	
Class Teacher	**	**	
School Counsellor	*	***	
School Principal	*	**	*
Transition Care Coordinator	*		
A support person (e.g. relative, friend)		*	



Narrative Responses of Parents/Carers

- “They are very informative, they listen to me and communicate well with me.”
- “It is helpful to find out about ad hoc services that are available. They also help with NDIS by providing information.”
- “The parent benefits as well as the child. It helps you to feel not so alone.”
- “The clinic really helps me. I do not have words to say how much I appreciate it.”



Room for Improvement: Suggestions from Parents/ Carers

- Communication/co-ordination with other agencies could be better
- There is a need for more staff such as psychiatrist, psychologist, occupational therapist, speech therapist
- It would be good if the clinic was available 3 days/week instead of the current 2 days/week
- It would be good if the parent could get an appointment when a problem arises vs having to wait for a scheduled appointment



Conclusions

- Survey of parents (N = 13) conducted 2012-2013
- Six common concerns reported (number of responses $N \geq 10$)
- Survey of parents/carers (N = 13) conducted 2017
- Three common concerns reported (number of responses $N \geq 10$)



Conclusions cont.

- Of 13 possible worries or concerns, parents/carers reported the clinic had been helpful in doing something to address 12 of these issues
- Suggested improvements include greater access to mental health professionals, to allied health therapy services, more frequent clinic visits and the ability to attend the clinic on an unscheduled basis when the need arises.
- The clinic provides a unique service to a target population that has high numbers of families from various cultural and linguistic backgrounds. Satisfaction with the service is very high and many expressed how much they value having access to this service.



Acknowledgements

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