The use of ICF–CY in very young children with developmental disorders

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Introduction

National outcome measures of children and youth services collect standardised data. In Australia the instruments for this purpose are the HONOS-CA (Health of the Nations Outcome Scale—Child and Adolescent), SDQ (Strength and Difficulties Questionnaire), FIHS (Factors Influencing Health Status) and GAF (Global Assessment of Functioning) scores from the DSM. The Experts Committee on Child and Adolescent Mental Health frequently questioned the reliability of the above measures for very young children who are not attending regular school. This study focused on the use of ICF–CY in assessing the level of functioning of this age group.

Aims of the study

The aims of the study were twofold:
1) to assess the suitability of ICF–CY in very young children
2) to study the level of functioning in the sample group.

Method

ICF–CY data was collected from twelve children below 7 years of age presenting at the Child and Adolescent Community Service. Data used to complete the questionnaire were collected from direct observation of the client, written records and key informants. Descriptive statistics were used to analyse the data.

Results

Demographic characteristics of the sample

- The mean age of the sample was 54.5 months i.e. 4.54 years with range from 49 to 83 months (i.e. 4 years and 1 month to 6 years and 11 months)
- The gender distribution favoured males over females with 10 of 12 being males and 2 of 12 being females.

- The children all came from Anglo Saxon backgrounds and were living with their parents in urban areas.
- Children in the sample where diagnosed as having Autism and had no other concurrent medical diagnosis.

Data relating to the suitability of ICF- CY

- Time spent coding the questionnaire varied from 15 to 30 minutes with mean time being 20.33 minutes. It was observed that the time spent in coding reduced with increase in practice with the tool.
- The ease of the use of ICF–CY was found to vary between medium to easy, again depending on the practice with the tool.
- The ICF–CY codes were found to be very meaningful for clarifying child characteristics and were also found to be culturally sensitive.

Data relating to level of functioning of the sample

Body functions

ICF–CY code	Description	Mean rating	Range
B1	**Mental functions**		
B110	Problems being alert and awake	.09	0-1
B120	Problems with task requiring thinking	3	2-4
B134	Problems falling or staying asleep	.55	0-2
B140	Problems paying attention	2.9	2-4
B147	Problems with clumsiness or coordination	1.5	1-2
b156	Problems distinguishing shapes, sounds and smells	2.4	1-4
B3	**Voice and speech functions**		
	Problems making sounds/ saying word	2.5	1-4

Thus from the above data it appears that:

- there is no major problem being alert and awake
- maximum problems are experienced on tasks requiring thinking, followed by problems in paying attention
- there are moderate levels of problems experienced in making sounds and saying words.

Activities and Participation

ICF–CY code	Description	Performance qualifier mean	Range	Capacity qualifier mean	Range	Performance - capacity
D1	**Learning and applying knowledge**					
D120	Problems mouthing, touching or tasting	1	0-3	.6	0-3	.4
D131	Problems playing	2.5	2-3	1.9	1-3	.6
D133	Problems using words, phrases or sentences	3.5	2-4	2.5	1-4	1
D137	Problems using concepts e.g. amount	3.4	0-4	2.6	1-4	.8
D140	Problems learning to read	3.3	0-4	2.5	0-4	.8
D145	Problems learning to write	3.4	0-4	2.5	0-4	.9
D150	Problems learning to calculate	3.7	2-4	2.7	1-4	1.

From the above data it appears that:

- Regarding performance

The greatest difficulty is experienced in the area of calculating, followed by problems using words and phrases; this is followed by difficulty in using concepts and learning to write and read.

- Regarding capacity

The greatest scope for improvement lies in the area of learning calculation, followed by learning to read, write and use concepts. Since children were very young and formal education had just started, it was difficult to predict their capacities.

ICF–CY Code	Description	Performance qualifier	Range	Capacity qualifier	Range	Performance - capacity
D2	**General tasks and demands**					
D210	Problems performing single task or responding to single communication	2.3	1-3	1.4	0-3	.9
D220	Problems performing multiple tasks	3.8	3-4	2.7	2-3	1.1
D230	Problems following the requirements of a daily routine	3.6	3-4	2.6	2-3	1
D235	Problems being consistent in behaviour from day to day	3.5	3-4	2.6	2-3	.9

From the above data it appears that:

- Regarding performance

The greatest difficulty is experienced in the area of performing multiple tasks and responding to multiple commands/commands with multiple components. This is followed by problems following the requirements of daily routine, and problems being consistent in behaviour from day to day. There are fewer problems in performing a single task or responding to a single communication.

- Regarding capability

There appears to be greatest scope for improvement in the area of performing multiple tasks, followed by following daily routine, being consistent in behaviour from day to day, and following single commands. This also depends very much on the course that a child's development takes, because for many children with Autism, responding to multiple tasks continues to be a problem throughout their life.

ICF–CY Code	Description	Performance qualifier	Range	Capacity qualifier	Range	Performance - capacity
D3	**Communication**					
D310	Problems understanding what others say	3.1	2-4	2.3	1-4	.8
D315	Problems understanding the meaning of gestures/pictures	3.1	2-4	2.3	1-4	.8
D330	Problems speaking	3.3	1-4	2.5	1-4	.8
D331	Problems making different vocal sounds	1.9	1-4	1.2	0-3	.7
D335	Problems using gesture pictures etc.	3.2	2-4	2.5	1-4	.7

As per the above table:

- Regarding performance

The maximum difficulty is experienced in the area of speaking, followed by problems using gestures, problems understanding what others say and the meaning of gestures/pictures, in that order.

- Regarding the scope for improvement in functioning

There appears to be maximum possibility for improvement in the area of speaking, understanding meaning of pictures and gestures, and understanding what others say. This is followed by problems making vocal sounds and problems using gesture pictures.

However the course of Autism is highly variable and degree of improvement depends, to some extent, on the interventions a child receives.

ICF- CY Codes	Description	Performance qualifier	Range	Capacity qualifier	Range	Performance - capacity
D4	**Mobility**					
D410	Problems sitting up or getting to stand	0	0	0	0	0
D415	Problems remaining seated/standing when required	1.8	2-3	.9	0-2	.9
D440	Problems using hands, fingers / thumbs	1.8	1-3	.7	0-2	1.1
D445	Problems using hands and arms	.8	0-2	.5	0-1	.3
D450	Problems walking	.1	0-1	0	0	.1

Overall there appears to be little problem in the mobility domain. The maximum problems observed appear to be in the area of finger dexterity and problems remaining seated or standing when required to do so. These also appear to be the areas with maximum scope of improvement. Mild problems in fine motor co-ordination have always been reported in Autism

ICF–CY Codes	Description	Performance qualifier	Range	Capacity qualifier	Range	Performance - capacity
D5	**Self care**					
D510	Problems washing self	2.8	1-4	1.7	1-4	1.1
D535	Problems using toilet	2.1	0-4	1.3	0-2	.8
D540	Problems dressing self	2.8	1-4	1.8	0-4	1.
D550	Problems eating	1.9	0-4	1.4	0-4	.5
D565	Problems avoiding harm to self	3.6	3-4	2.9	1-4	.7

As from the above data it appears that:

- Regarding performance

There appears to be greatest difficulty in the area of avoiding harm to self, followed by problems washing and dressing self. The maximum scope of improvement appears to be in the area of washing and dressing self, followed by problems using the toilet.

Avoiding harm to self is a continuing problem which has been noticed clinically, even in older age groups.

ICF–CY Codes	Description	Performance qualifier	Range	Capacity qualifier	Range	Performance - capacity
D6	**Domestic life**					
	Problems participating in activities of the household	3.9	3-4	3.3	3-4	.6

Though there appears to be problems with performance in the area of participating in activities of the household, there does not seem to be much capacity for performance in this area at present. This is not surprising since the individuals in question are all preschool children and the major focus of the parents has been getting the children to learn self help skills rather than participating in household chores.

ICF–CY Codes	Description	Performance qualifier	Range	Capacity qualifier	Range	Performance - capacity
D7	**Interpersonal interactions and relationships**					
D710	Problems relating to others	3.9	3-4	3.3	3-4	.6

There appears to be a very high degree of disability in the area of Interpersonal interactions and relationships, since the performance in this area indicates poor level of functioning and limited capacity to gain from the ideal environment. This is not surprising as the main disability in Autism is difficulty with interpersonal relationships. This is the main cause why these children are not able to participate in many social and community activities in life.

ICF–CY Codes	Description	Performance qualifier	Range	Capacity qualifier	Range	Performance - capacity
D8	**Major life areas**					
D811	Problems playing with others	3.5	3-4	2.8	2-4	.7
D820	Problems participating in preschool education	3.8	3-4	3	2-4	.8
D860	Problems using money	4	4	4	4	0

ICF–CY Codes	Description	Performance qualifier	Range	Capacity qualifier	Range	Performance - capacity
D9	**Community social and civic life**					
	Problem in engaging in activities in school / neighborhood	4	4	3.3	3-4	.7

In all of the above areas there appears to be a very high level of disability, and a limited capacity to improve with experience. This is particularly true for problems using money but also, problems with other children, and problems in engaging in neighbourhood activities.

Environmental factors

ICF–CY	Description	Facilitator (+) / barrier (-)
E3	**Support and relationships**	
E310	Support of immediate family	+3.1
		0
E 315	Support of extended family	+1.6
		0
E 320	Support of friends	+1
		-1
E 325	Support of acquaintances, peers and neighbours	+1
		-1
E 330	Support of persons in authority	+2
		0
E 340	Support of personal care providers and personal assistants	+1.5
		0
E 350	Support of domesticated animals available	N/A
E 355	Support of health professionals available	+3
		0

The support of immediate family is seen as an important facilitator, followed by the support of health professionals and support of persons in authority. The support of friends and the support of acquaintances, peers and neighbours have been found to be both a facilitator and a barrier. Whether they are either a facilitator or barrier was found to depend upon their understanding of Autism.

ICF–CY codes	**Description**	**Facilitator (+) / barrier(-)**
E4	**Attitudes**	
E 410	Favourable attitudes of immediate family	+2
		0
E415	Favourable attitudes of extended family	+1.5
		-1
E 425	Favourable attitudes of acquaintances, peers and neighbours	+1.3
		-1.7
E 430	Favourable attitudes of persons in authority	+2
		0
E 440	Favourable attitudes of personal care providers and personal assistants	N/A
E450	Favourable attitudes of health professionals	+3
		0

The favourable attitudes of health care professionals were found to be an important facilitator followed by the favourable attitudes of immediate family and people in authority. The most important barrier appears to be the attitude of acquaintances, peers and neighbours which is also seen as a facilitator in some cases. Similarly the attitude of the extended family is seen as both a facilitator and a barrier. This again depends upon their understanding of Autism. This also opens up the possibility for short focused psycho-education intervention, which has great potential in terms of respite and help to parents.

ICF–CY codes	Description	Facilitator(+) / barrier(-)
E5	**Services, systems and policies**	
E 540	Availability of transportation services, systems and policies	N\A
E 570	Availability of social security services, systems and policies	+2.6
		0
E 580	Availability of health services, systems and policies	+2.3
		0
E 585a	Availability of educational services, systems and policies	+1.8
		-1
E585 b	Availability of special education services, system and policies	+1.3
		-1.3

The availability of social security services, systems and policies is seen to be an important facilitator followed by the availability of health services. The availability of educational (and special educational) services, systems and policies have been found to be both a facilitator and a barrier.

Parents report great variation in the attitude of different schools towards Autism. Some schools are very supportive, where as some schools appear to have a very negative attitude.

Discussion and conclusions

Overall ICF–CY has been found to be a useful instrument for use in very young children (i.e. 6 years old and less). It has also been found easy to use—with ratings of medium to easy, depending on the user's practice with the tool. The ICF–CY codes were found to be very meaningful for clarifying child characteristics and were also found to be culturally sensitive.

Regarding the level of functioning in this sample, the greatest disability was found to be in the domain of problems in engaging in activities in school and neighbourhood, interpersonal interactions and relationships, and problems participating in activities of the household.

In this regard it needs to be borne in mind that this is a cross-sectional sample of children with Autism Spectrum Disorders and that disability can change over time and through developmental stages. Just as disability affects development so too does development affect disability. For example, in the domain of Activity and

Participation, even though it appears that the children in this sample have limited capacity for reading, writing and calculation it may not reflect the true capacity for these children. As the mean age of children in the sample is less than 5 years, and delays in development are well known in Autism, the picture is more fluid and subject to change over time, e.g. if the same individuals were to be re-assessed at 9 years.

In regard to barriers and facilitators, it has been observed that some factors such as the availability, support and attitudes of health care professionals have been perceived to be a facilitator for all individuals. However, there are also some factors which have been both facilitators and barriers, such as the attitude of extended family members and education departments. Whether a factor is a facilitator or a barrier was found to be dependent on the level of knowledge and information that individuals and agencies have about developmental disabilities in general and Autistic Spectrum Disorders specifically (due to the nature of the sample). For example, the behaviours which appear to be 'temper tantrums' to the uninformed can be seen as 'a response to disturbance in routine' by those who are well informed on the disorder.

Thus we can **conclude** by saying that ICF–CY is an appropriate and sensitive instrument which is relatively easy to use for assessing the level of functioning in this sample.
Secondly that, children of less than 6 years who come to the attention of mental health service are more likely to suffer from developmental disorders and particularly, as in this sample, pervasive developmental disorders such as Autism.
Thirdly, the level of information which individuals and agencies have regarding childhood disorders, affects their capacity to respond as either barriers or facilitators.

Suggestions

Given the advantages of using ICF- CY I would like to recommend the use of the ICF–CY in children of six years and under. It would confer several advantages in mapping the trajectories of childhood disorders and studying the influence of environmental facilitators and barriers. I would also like to suggest that it would help to have a global rating for each domain of performance and capacity to facilitate research comparisons and ease in clinical decision making. Thirdly I would like to suggest that psycho-education be provided to the community in general, and to the educational agencies and extended family of children with Autism in particular (regarding the nature of the disorder). This would facilitate the integration of these children and their families into the community.

References

Goodman R 1997. Strengths And Difficulties Questionnaire, A research note, Journal of Child Psychology and Psychiatry 38:581–586

Gowers SG, Harrington RC, Whitton A, Lelliot P, Wing J, Beevor A et al. A brief scale for measuring the outcomes of emotional and behavioural disorders in children: HoNOSCA. British Journal of Psychiatry 174:413–416

Simeonsson RJ & Leonardi M 2004. ICF version for Children and Youth: development and field trial. Paper presented at WHO Family of International Classifications Network Meeting, Reykjavik, October.

Wing TR, Curtis RH & Beever AS 1996. Health of Nations Outcome Scales, Report on research and development, July 1993–December 1995. London: Royal College of Psychiatrists.