

## Carer experiences supporting older people with Intellectual Disability

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## ABCD Clinic

- Ageing and Behaviour Changes in Developmental Disability (ABCD) Clinic at Concord Hospital
- Case conference - Rehabilitation physicians, psychiatrists, geriatricians, RNs, allied health professionals, case workers, Persons Responsible .....



## Aims

- To profile the difficulties experienced by formal carers of people with Intellectual Disability.
- To compare the assessed need for support with level of perceived difficulty with each dimension of caring.



Caregiving Difficulty scale- Intellectual Disability (McCallion, McCarron and Force 2005)



## Participants and method

- People referred to the Clinic over a six month period who lived in supported accommodation;
- Documented the amount of support they needed in each area;
- Residential support workers caring for those people;
- Questionnaire about how difficult they thought it was for them to provide the support in the past week.



## Modified Functional Independence Measure

- |                                                                                                                                                                              |                                                                                                                                                                                                        |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> <li>• Eating</li> <li>• Grooming</li> <li>• Bathing</li> <li>• Dressing upper body</li> <li>• Dressing lower body</li> </ul>              | <ul style="list-style-type: none"> <li>• Comprehension</li> <li>• Expression</li> <li>• Social interaction</li> <li>• Problem solving</li> <li>• Memory</li> </ul>                                     |
| <ul style="list-style-type: none"> <li>• Toileting</li> <li>• Bladder management</li> <li>• Bowel management</li> </ul>                                                      | <p><b>'1' – Independence or equipment</b></p> <p><b>'2' – Supervision or set up</b></p> <p><b>'3' – Moderate contact assistance by helper</b></p> <p><b>'4' – Maximal/total contact assistance</b></p> |
| <ul style="list-style-type: none"> <li>• Transfer bed/chair/wchr</li> <li>• Transfer toilet</li> <li>• Transfer tub/shower</li> <li>• Walk/wchr</li> <li>• Stairs</li> </ul> |                                                                                                                                                                                                        |

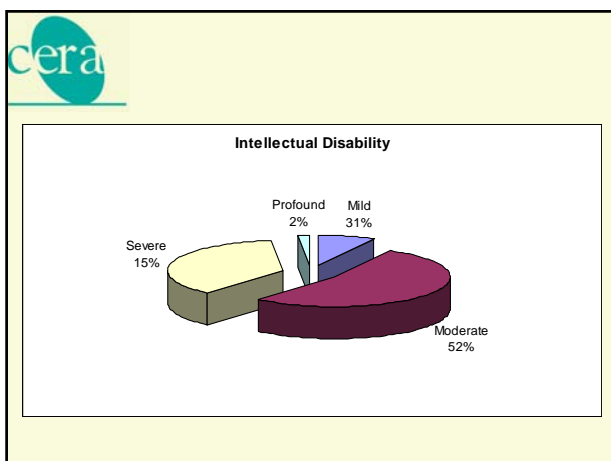
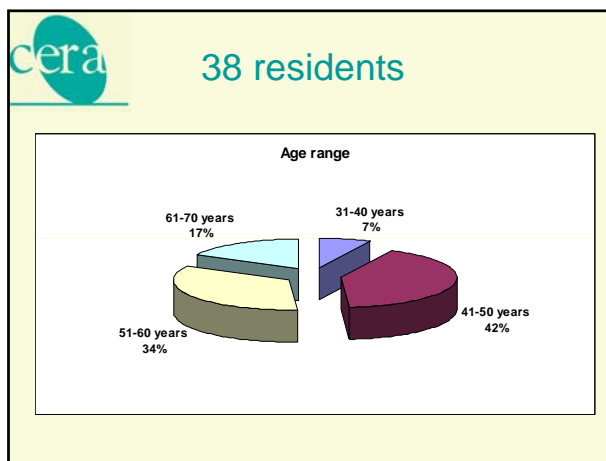
**Carers' questions**

- '1' – not difficult/didn't happen
- '2' – slightly difficult for me
- '3' – moderately difficult for me
- '4' – major difficulty for me

Aspect of Care	Not Difficult, didn't happen	Slightly difficult for me	Moderately difficult for me	Major Difficulty for me
Eating/Drinking				
Brushing teeth, combing hair, shaving				
Showering, washing all over				
Dressing upper body				
Dressing lower body				
Undressing for toileting, using toilet paper, dressing again				

**Why are any of these things difficult?**


Issue	Yes/No
We don't really have the right equipment	
The design of the residence is inadequate	
This person or another in the house takes a long time one-to-one and I need another carer on my shift to pay proper attention to all of them	
There are conflicts between the person and other residents	
There are conflicts between me and other carers about the person	
There are conflicts between me/us and the Person Responsible	
It takes too long/or takes longer than it did when I started with this person	
This person has changed - s/he is deteriorating in her/his abilities and his new needs are not recognized by the administration	
I feel I need more training in communication and behaviour to be able to assist this person properly	
I feel I need more training in ageing issues to be able to assist this person properly	
There are things going on in my home life and I feel hassled by everything this week	




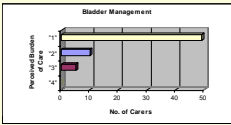
- 58 Carers**
- 58 paid carers– 10 males and 48 females (5 carers did not complete demographic info).
  - Age range was 19-58 years
  - They had been residential care workers an average of 9.6 years (range 6 months-30 years)
  - They had known the client about whom they completed the survey for an average of 5.03 years (range 6mths-18 years). The median time was 3 years.

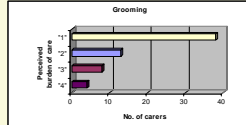


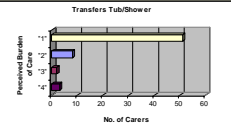
64 resident-carer pairs




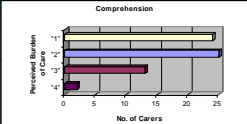


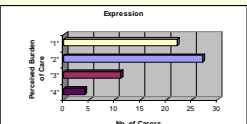


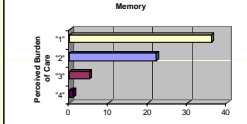


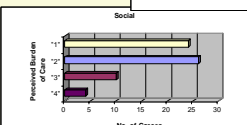


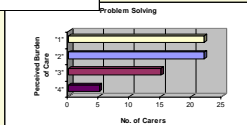

















## Eating

	Perceived burden '1'	Perceived burden '2'	Perceived burden '3'	Perceived burden '4'
<b>FIM '4'</b>	3	1		
<b>FIM '3'</b>	7	7	5	
<b>FIM '2'</b>	5	3		
<b>FIM '1'</b>	24	7	1	



## Social interaction

	Perceived burden '1'	Perceived burden '2'	Perceived burden '3'	Perceived burden '4'
<b>FIM '4'</b>	2	3	1	2
<b>FIM '3'</b>	13	17	8	2
<b>FIM '2'</b>	4	2	1	
<b>FIM '1'</b>	4	4		



Aspect of Care	Correlation	significance
<b>Motor</b>		
Eating	.288	.022 *
Grooming	.372	.003 **
Bathing	.300	.017 *
Dressing (upper body)	.428	.000 **
Dressing (lower body)	.488	.000 **
Toileting	.208	.101
Bladder management	.221	.081
Bowel management	.294	.019 *
T/i Bed/chair/wheelchair	.427	.000 **

**cera** **Correlations**

- For personal care, elimination and mobility items there was a significant correlation between assessed level of need and perceived carer burden
- For the cognitive items there was no correlation.

**cera**

- Age groups - no significance
- Level of Intellectual Disability – no significance
- Age of carer, experience of carer – no significance

**cera** **More difficulty if resident's behaviour was changing**

**Graph 3 Influence of client stability**

Category	Stable behaviour	Deteriorating
Continence FIM	1.5	2.0
Continence difficulty	1.2	1.3
Mobility FIM	1.5	2.2
Mobility difficulty	1.1	1.5
Cognition FIM	2.5	2.6
Cognition difficulty	1.7	2.0
Personal Care FIM	1.3	2.7
Personal Care difficulty	1.3	2.0

**cera** **What would help**

- More equipment
- More training in what to expect and how to respond
- Different resident mix
- Another person on the shift


**cera** **Other studies**

- Alterations in function from what is expected can lead to an increase in carer stress and higher staff turnover in care-giving facilities


White, Edwards, Townsend-White 2006)

**cera** **Results summary**

- In this group of people with challenging behaviour:
- Most carers did not find it difficult to provide physical assistance whatever the level of care required
- Some carers found difficulty with physical domains if the person needed a lot of assistance and needed equipment was not available




- There was little correlation between carer perception of difficulty and assessed need for support in the cognitive domains;
- The main reason for difficulty in those in whom there was difficulty was that the person's behaviour had been 'deteriorating'.



## Conclusions

- Carers do not generally have difficulty providing physical care
- Carers do not generally have difficulty providing cognitive support
- Carers have some difficulty providing cognitive support if the person's behaviour is changing; and there is no 'back up' for the amount of attention that they must provide



## Recommendations

- To minimise 'burn-out' in care workers, review assessments of support hours should be conducted annually in people over the age of 40 years.



## Acknowledgments

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**Department of Ageing, Disability & Home Care**

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