

# Partnerships with the advocates of people with an intellectual disability who attend an emergency department.

Early observations from part of a PhD project.

David Foley

Supervisors:

Professor Helen McCutcheon

Dr Lynne Barnes

# Background

- Mr Gadaleta, 28 years old
  - Cerebral palsy, microcephaly with resultant spastic quadriplegia, and epilepsy.
  - Incapable of verbal communication
- Taken to ED by ambulance from institutional care after his support worker noticed that “he was sitting on the floor..., he was sweating and was not his usual smiling self... he didn’t look normal”

South Australian Coroner, 2001,

[http://www.courts.sa.gov.au/courts/coroner/findings/findings\\_2001/gadaleta.finding.htm](http://www.courts.sa.gov.au/courts/coroner/findings/findings_2001/gadaleta.finding.htm)

## RN's report of conversation with Mr Gadaleta's support worker (SW):

SW: I think he has abdominal pain

RN: Well what makes you think that?

SW: He keeps pulling his knees up to his chest (and) also he keeps putting his fingers in his mouth and he's moaning all the time

RN: Well what is he normally like?

SW: He likes to lay on the floor curled up in a ball... and he puts everything into his mouth - fingers, rocks, everything in his mouth all the time. This is why I think he's got pain, but that's how he always is'.

## RN's report of conversation with SW:

RN (to coroner): I found it difficult... to know whether he had pain or not. ...he didn't look to be in pain and with the moaning she also said that that was the only way he could communicate, so it didn't sound as if that were any different. I did note when I was working him up that his hands were almost a purpley colour and I said to the support worker, 'His hands are a very odd colour'

SW: 'They're always that colour'

RN (to coroner): so there were things about him that normally would trigger things for me but everything I asked (his support worker) about she would say was normal.

Coroner: The RN did not record any of these issues in the casenotes at the time. I would have thought that such florid symptoms would have been noted



# Coroner on Communication

"There is a clear dispute on the evidence between (his support worker and the RN) about this conversation. The (support worker) denied that she told (the RN) that Mr Gadaleta always had his knees up to his chest, or that she said he had a history of putting things in his mouth, or that she said he often moaned or that his hands were normally discoloured"

"I am inclined to accept (Mr Gadaleta's support worker) on this issue"

"It seems to me that a significant communication breakdown occurred between (the RN) and his support worker on the night. The information about Mr Gadaleta putting things in his mouth appears to have come from (a different source)."

"This breakdown in communication was a potentially serious one which could have had quite serious consequences, particularly in a case where, as here, Mr Gadaleta could not communicate for himself."

## CORONERS ACT, 1975 AS AMENDED



An Inquest taken on behalf of our Sovereign Lady the Queen at Adelaide in the State of South Australia, on the 2<sup>nd</sup> and 3<sup>rd</sup> and 17<sup>th</sup> of July 2001 and the 24<sup>th</sup> of August 2001, before Wayne Cromwell Chivell, a Coroner for the said State, concerning the death of Mr Gadaleta.

I, the said Coroner, find that Mr Gadaleta, aged 28 years, late of 123 Smith St, Best Care House\*\* died at the emergency department\*\*\*, South Australia on the 30<sup>th</sup> of July 1999 as a result of peritonitis and septic shock complicating perforation of the terminal small bowel. I find that the circumstances of the death were as follows:

**'Peritonitis and septic shock complicating perforation of the terminal small bowel by a swallowed screw top lid of a Coca-Cola bottle.'**

\*\* Not actual address

\*\*\* Hospital de-identified



# Overall Purpose of Study

Describe what happens to the person with an intellectually disability (ID) when they are in an emergency department.

Investigate:

The care that they receive,  
the treatment that is administered  
and the communication that occurs with them

# Methods

- Standardised Picker Institute (Europe) NHS, UK *Emergency Department Questionnaire* completed by support workers
- Interview people with an ID who have recently attended an Emergency Department (ED).
- Case note review of ED attendance
- Focus groups of support workers
- Interviews of support workers



# Results

- For this presentation only presenting some data and themes from support worker focus groups and interviews.
- This is a very early report of analysis in progress.
- Data collection was only recently completed
- This is almost exclusively presented from the support worker's point of view.



## 2 Main Points from Support Workers

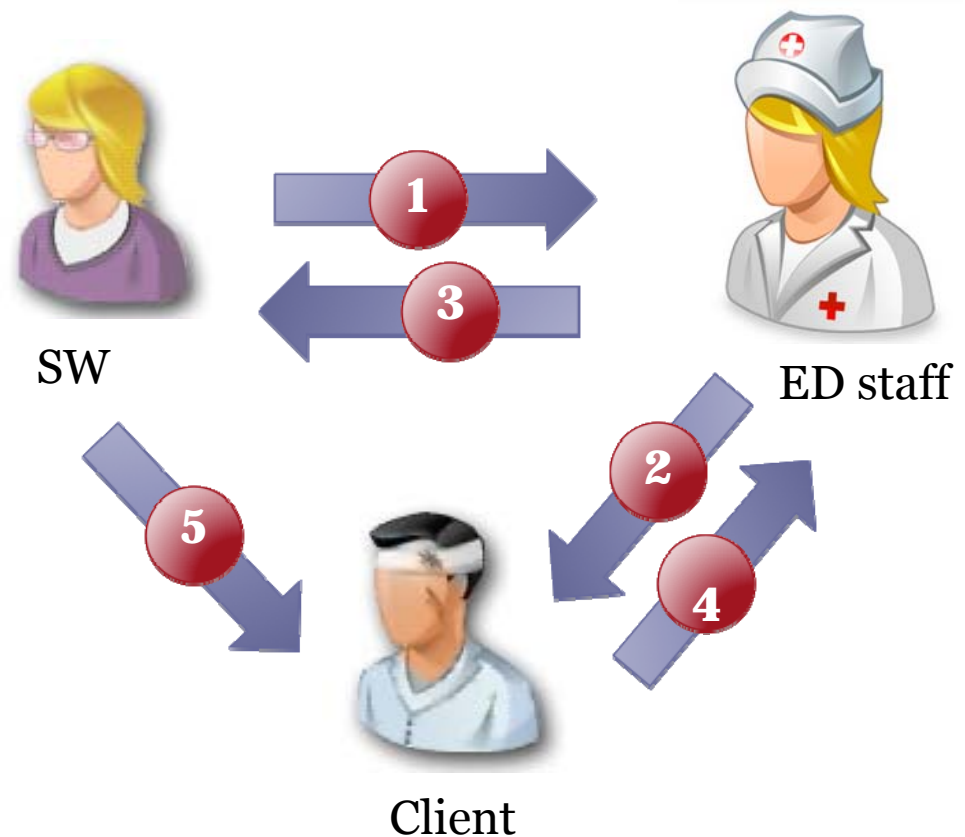
- Communication
- Advocacy

# Communication

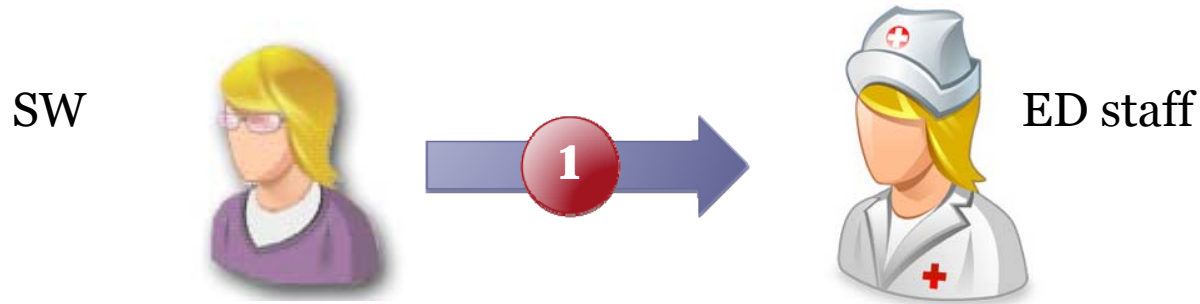
“This breakdown in communication.. could have had quite serious consequences... as Mr Gadaleta could not communicate for himself.”  
(State Coroner, 2001)

5 described

- 1. SW to ED staff
- 2. ED staff to client
- 3. ED staff to SW
- 4. Client to ED staff
- 5. SW to client
- 6. (Client to SW)



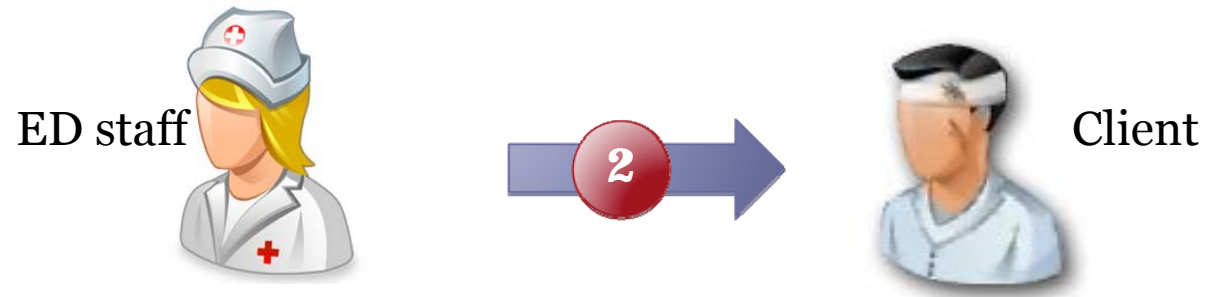
# 1. Communication: SW with ED staff



**You need to proactively state who you are.**

- "Tell them who I am instead of waiting to be asked or ignored. Give them some info about him... It is obvious who I am, that I know about my client and (I know) things about him that may be important to them."
- "If you just stand there they will talk around you and you will come across as not knowing anything because you are not offering any information."

## 2. Communication: ED staff to client



### Fear & Inexperience

- "The (nurses) told my client what they were doing"
- Didn't explain any further and "They didn't always let me know"
- If they know that the client understands (SW has to tell them) then they will explain.
- "I found that a lot of nursing staff are not really to sure how to relate to our clients and they (nurses) are frightened"
- If clients look 'more normal' the staff talk to them.
- They are afraid because they have had experiences when our clients have tried to bite or hit.

### 3. Communication: ED staff to SW

SW

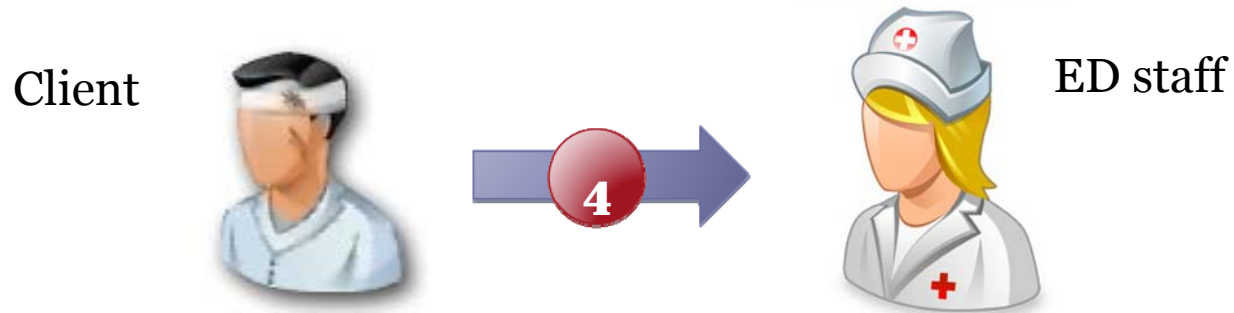


ED staff

#### Make Emergency Staff Know

- From an experienced support worker:
  - “Nurses wont talk to you if you don’t know about your client”
  - “They explained to me what was happening”
  - “In general they are pretty good at explaining what they are doing”
- For a very junior support worker on her first ED visit:
  - “They didn’t always let me know... I sat back because I didn’t know what was going on”

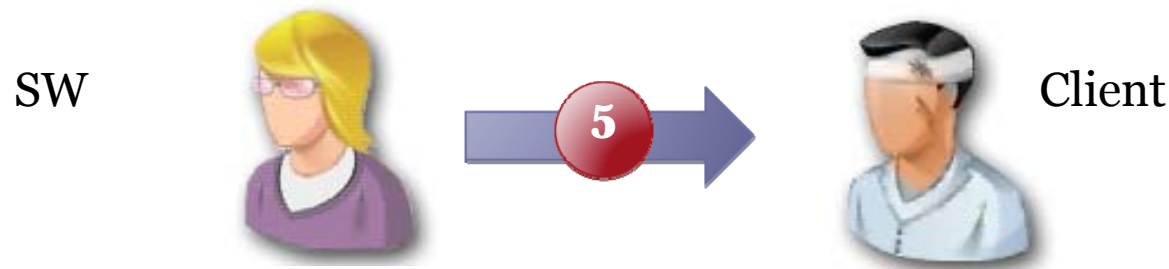
## 4. Communication: Client to ED staff



### Appearances & Behaviour Can Determine The Interaction

- If clients look 'more normal' the staff will initiate
- if client has an obvious intellectual disability ED staff will ignore

## 5. Communication: SW to Client



### Translating & Explaining

- "I tell them (ED staff) to talk to him, so that he knows what is happening. If they don't tell him then I will tell him what is happening and prepare him"
- SW described taking blood pressure and taking venous blood.

# Advocacy

- Important role
  - Recognised but not always understood or acted out
- Interviews and FG revealed how to do this.
- Often not understood by junior support workers, but learnt with experience.
- In FG agreed that in early years of being a support worker just accompanied the client and explained the care plan (which ED staff didn't understand)



Image used with permission

# Advocacy

To successfully advocate:

1. Make it clear that you know the client
2. Proactively describe them, before being asked
3. Indicate your special knowledge about the client (behaviours, responses, allergies, medications, last illness...) and give a clear rehearsed & researched history
4. Ask a lot of questions about everything in a polite and friendly way, explaining why you need to know.
  - Put in case notes and hand over to shift supervisor



# Advocacy

- You are indicating that you have special knowledge, that you are a professional and that you are like a parent.
- “You need to be a little bit pushy in the nicest possible way”
- Acting on their behalf by supporting their wishes.
  - If a client is stressed by having their BP measured, ask if it needs to be done.
  - If it can be explained that it is life saving then you might help to hold them.
  - However if it is routine and without good reason ask the nurse not to do it. (Acting with implied consent)

(BP measurement (particularly low BP) can be roughly determined by an experienced person without using a sphygmomanometer)



# Conclusion

- Experienced support workers were able to give very informed descriptions of how care is conducted in the ED
- This was in contrast to less experienced support workers, highlighting the importance of how to be an effective advocate
- Being an advocate is a usual role
  - ED staff need to recognise and encourage this role particularly from less experienced or quiet support workers.
- Communication needs to be initiated by support workers in a friendly insistent manner and from a well informed position.
  - This will aid their inclusion in their client's care

# Mr Gadaleta with hindsight...

"Hindsight is not necessarily the best guide to understanding what really happened. The past is often as distorted by hindsight as it is clarified by it."

AMOS ELON, *The Pity of It All*

- Perhaps....
  - The support worker:
    - could have been more assertive
    - could have asked more questions
  - The nurse
    - should have recognised the support worker's knowledge &
    - encouraged her role as advocate
  - A better partnership in which the support worker was respected and her advocacy role appreciated could have occurred.