

 Disability Means Possibility

**Communicating Pain:**  
"Distress may be hidden, but it is never silent"



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**Funding support**

- The Winifred & John Webster Charitable Trust (as managed by Perpetual) - \$20,000
- Lord Mayor's Fund - \$25,000

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**Some Background ...**

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Health Snapshot of Scope residential and respite services conducted in August 2004, indicated that 27% of the 214 people living in Scope supported accommodation and 60% of the 328 clients who access Scope respite services are not able to communicate in a way that is easily understood when they are in pain (Koutoukidis, 2004).

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At the time of this 'snapshot' and currently, Scope Procedures around the management of pain do not appear to consider the needs of people who are unable to communicate formally. They assume an ability to symbolically express pain.

Therefore there was a lack of clear guidance around how to 'listen to' and 'respond to' the needs of people in pain who communicate informally.

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Generally there is a growing concern within Scope services and beyond regarding the issues facing people who are unable to use speech to express their experience of pain

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So ... we began with a literature review.

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**We asked the following questions ...**

- What methods have been used to describe expression of pain in people who do not use speech?
- What methods have been used in other populations?
- What recommendations have been made?
- What gaps exist?

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**What did we learn from the literature?**

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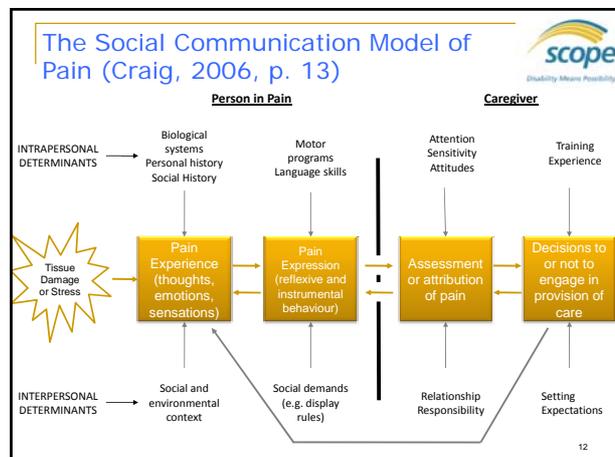
**Pain (International Association for the Study of Pain)**

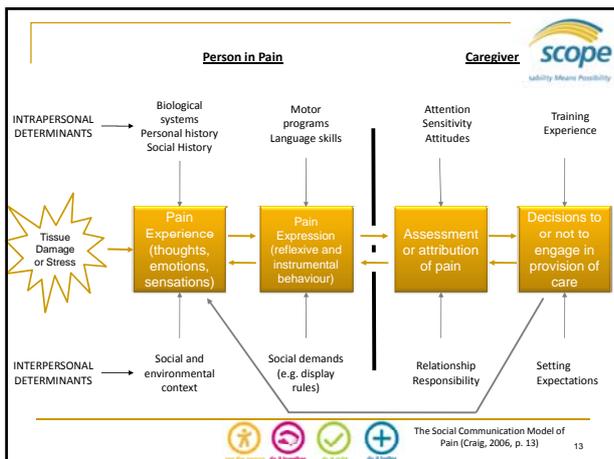
An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. Note: the inability to communicate verbally does not negate the possibility that an individual is experiencing pain and is in need of appropriate pain-relieving treatment. Pain is always subjective.

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### Experiencing Pain

- People with disabilities do experience pain
- Many people with cerebral palsy experience frequent pain
- There is a need to be aware of the impact of gastrointestinal issues on pain. They are sometimes linked with self-injurious behaviours
- People with disabilities experience pain with aging the same as people without disabilities (e.g. arthritis). Frequently, for people with physical disabilities, the aging process begins earlier.

### Perspectives About Pain

- Historical belief about insensitivity
  - Much evidence disproving wide-spread insensitivity
- Historical belief about permanent state of pain
- Everybody brings a bias that shapes the way that the pain of another person is perceived!

### Expressing Pain

- Gold standard – self-report is not possible for some people with disabilities
- Behavioural observations
  - Is the pain expressed the same way as people without disabilities or is it expressed differently?

### Tools for Assessing Pain

- General Tools for:
  - Infants - FAC
  - Children – behavioural, physiological, psychological (5 + visual analogue scales)
  - Adults – self-report scales such as the Brief Pain Inventory
  - Older adults – Abbey Pain Scale
- Tools for children with disabilities
  - Non-Communicating Children’s Pain Checklist (NCCPC)
- Tools for adults with intellectual disabilities
  - DisDAT
  - PADS

### Pain and Discomfort Scales (PADS) (Bodfish et al 2001)

- PADS + Pain Examination Procedure (PEP)
- Interaction with person and manipulation of limbs to elicit and localize pain sites
- Has been used with a broad range of people with severe disabilities

### Disability Distress Assessment Tool (DisDAT) Regnard et al 2007



- Developed by team of people working with people with intellectual disability and palliative care team
- Based on recognising and describing DISTRESS signals, which may or may not include pain signals
- A profile of distress and non-distressed behaviours
- Early stage of examining psychometric properties

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### Responding to Pain



- Parents respond by comforting
- Use of analgesics
- People with cerebral palsy have stated that they use various methods of pain management, however the methods rarely fully ameliorate pain
- Kerr et al (2006) – non-pharmacological interventions (e.g. Aromatherapy, warm baths, relaxed interactions).
- Pain management clinics are rarely used (for people with disabilities?)

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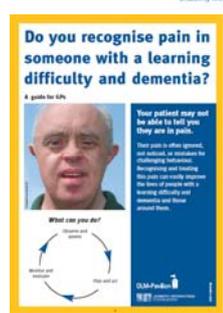
### Campaigns and Policy

- Raising awareness that people with disabilities DO experience pain, that must be responded to appropriately
  - Mencap: Death by Indifference
  - Health inequality reports
- Educating people with disabilities about pain
- Tools for expressing pain, such as the CAUS Hospital Kit

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### Campaigns and Policy

- Pain management for older people with learning difficulties and dementia - Kerr, Cunningham & Wilkinson from Joseph Rowntree in UK
  - Resources for staff, GPs and carers
    - <http://www.jrf.org.uk/publications/pain-management-older-people-with-learning-difficulties-and-dementia-0>



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### Conclusions



There has been improvement over the past 10 years, but there is still a long way to go.

Pain experience	Pain expression	Assessment of pain	Provision of care
<ul style="list-style-type: none"> <li>Profiles of knowledge</li> <li>Individual</li> <li>Condition</li> </ul>	<ul style="list-style-type: none"> <li>Education of people with disabilities about expressing pain</li> <li>Vocabulary support</li> </ul>	<ul style="list-style-type: none"> <li>Campaigns to raise sensitivity</li> <li>Consistent tool use</li> <li>Clear expectations</li> </ul>	<ul style="list-style-type: none"> <li>Pathways for response</li> <li>Role of specialist nurse</li> <li>Care for the carers</li> </ul>

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### Where to from here?

Scope intend to ...

- Identify how existing tool(s) may need to be modified to be of relevance to people with do not communicate formally;
- Investigate Disability Support Worker capacity and confidence in relation to the use of the tool(s);
- Identify the reliability of the tool's application across different users;
- Develop guidelines for the application of the tool in practice settings.

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## References



Abbey, J., Piller, N., De Bellis, A., Esterman, A., Parker, D., Giles, L., et al. (2004). The Abbey pain scale: a 1-minute numerical indicator for people with end-stage dementia. *International Journal of Palliative Nursing*, 10(1), 8-13.

Bodfish, J. W., Hager, V. H., Doocron, J. M., Doocron, J. R., & Symons, F. J. (2006). Issues in pain assessment for adults with severe to profound mental retardation. In T. F. Oberlander & F. J. Symons (Eds.), *Pain in individuals with developmental disabilities* (pp. 173-192). Baltimore: Paul H. Brookes.

Bodfish, J. W., Hager, V. H., Doocron, J. R., & Symons, F. J. (2001, revised 2008). Identifying and measuring pain in persons with developmental disabilities: A manual for Pain and Discomfort Scale (PADS). Morganton, North Carolina: Human Development Research & Training Institute, J. Iverson Riddie Developmental Center.

Breau, L., McDonald, P. J., Finlay, A., & Camfield, C. (2004). Non-communicating Children's Pain Checklist - Revised (NCCPC-R), from [http://www.aboutkidshealth.ca/SharedPDFs/AKH\\_Breau\\_everyday.pdf](http://www.aboutkidshealth.ca/SharedPDFs/AKH_Breau_everyday.pdf)

Carr, E., & Owen-DeSchryver, J. (2007). Physical illness, pain, and problem behavior in minimally verbal people with developmental disabilities. *Journal of Autism and Developmental Disorders*, 37(3), 413-424.

Charlton, J. E. E. (2005). Pain issues in individuals with limited ability to communicate due to cognitive impairment, Core curriculum for professional education in pain available from [www.sage-pain.org](http://www.sage-pain.org)

Cleveland, C. S. (2009). The Brief Pain Inventory Available from <http://www.mbanderson.org/pdf/bpi-userguide.pdf>

Craig, K. D. (2008). The construct and definition of pain in developmental disability. In T. F. Oberlander & F. J. Symons (Eds.), *Pain in children and adults with developmental disabilities* (pp. 7-18). Baltimore: Paul H Brookes.

Defrin, R., Pick, C. G., Perez, C., & Carmel, E. (2004). A quantitative somatosensory testing of pain threshold in individuals with mental retardation. *Pain*, 108(1-2), 58-65.

Dodd, K., & Gattard, J. (1998). *Feeling poorly: A complete assessment and training pack to help people with learning disabilities communicate effectively about symptoms of illness and pain*. Brighton, East Sussex: Pavilion.

Donovan, J. (2002). Learning disability nurses' experiences of being with clients who may be in pain. *Journal of Advanced Nursing*, 38(5), 458-466.

Eipel, J. M., Kerlin, D., & Jensen, H. P. (2003). Pain treatment in persons with cerebral palsy: Frequency and helpfulness. *American Journal of Physical Medicine & Rehabilitation*, 81(4), 291-296, 30.

Gibson, L., Matthews, D., & Regnard, C. (n.d.). *The Disability Distress Assessment Tool*

Hunt, A., Mastrogiorgos, K., Calderon, A., & Sreen, K. (2003). Not knowing - the problem of pain in children with severe neurological impairment. *International Journal of Nursing Studies*, 40(2), 171-183.

Kerr, D., Cunningham, C., & Wilkinson, H. (2006). *Responding to the pain experiences of people with a learning difficulty and dementia*. York: Joseph Rowntree Foundation.

MEVCAP (2007). *Death by indifference: Following up the treat me right! Report*. London: Author.

Oberlander, T. F., & Symons, F. J. (Eds.) (2006). *Pain in children and adults with developmental disabilities*. Baltimore: Paul H. Brookes.

Regnard, C., Reynolds, J., Watson, B., Matthews, D., Gibson, L., & Clark, C. (2007). Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). *Journal of Intellectual Disability Research*, 51(4), 277-292.

Schoey (2008). Pain and disability in an ethical and social context. In T. F. Oberlander & F. J. Symons (Eds.), *Pain in children and adults with developmental disabilities* (pp. 19-39). Baltimore: Paul H Brookes.

Symons, F. J., Shinde, S. K., & Giles, E. (2008). Perspectives on pain and intellectual disability. *Journal of Intellectual Disability Research*, 52(d), 275-286.



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