

**diabetes is
different for
children**

It is time for change



**Hvidøre Study Group and DAWN Youth –
towards a new paradigm for paediatric
diabetes care**

Hilary Hoey, Ireland

The Hvidøre study group



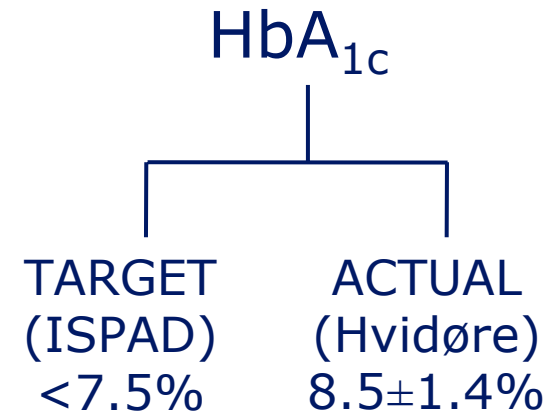
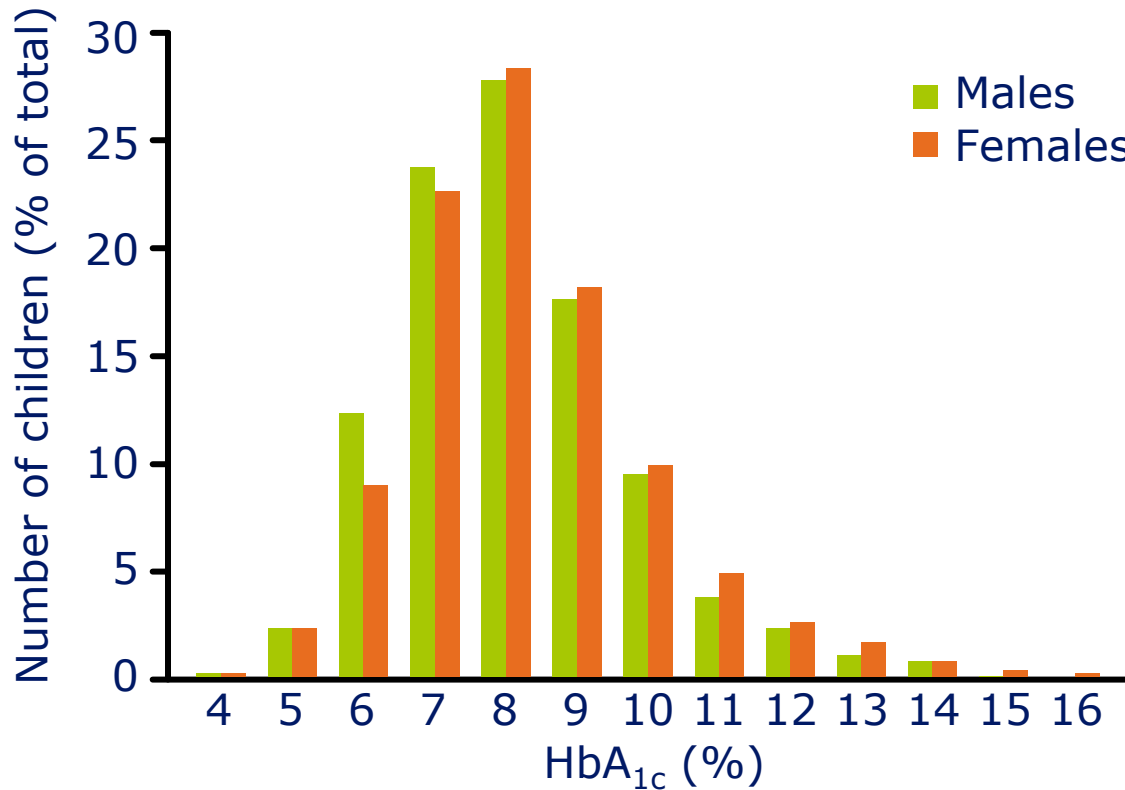
- 3 major international studies (1995, 1998, 2005)
- More than 2000 children and adolescents with type 1 diabetes
 - 21 centres
 - 19 countriesEurope, N America, Japan & Australia
- HbA_{1c} was centrally analysed

H.J. Aanstoot, Netherlands;
J. Aman, Sweden; F. Cameron, Australia; L. Castano, Spain; F. Chiarelli, Italy; D. Daneman, Canada; C. De Beaufort, Luxembourg; H. Dorchy, Belgium; H. Hoey, Ireland; R.W. Holl, Germany; E.A. Kaprio, Finland; R.W. Holl, Germany; E.A. Kaprio, Finland; F. Kaufman, USA; M. Kocova, Macedonia; P. Martul, Spain; H. Mortensen, Denmark; P. Njolstad, Norway; M. Phillip, Israel; J.J. Robert, France; K.J. Robertson, U.K; E. Schoenle, Switzerland; P.G.F. Swift, U.K; T. Urakami, Japan; M. Vanelli, Italy

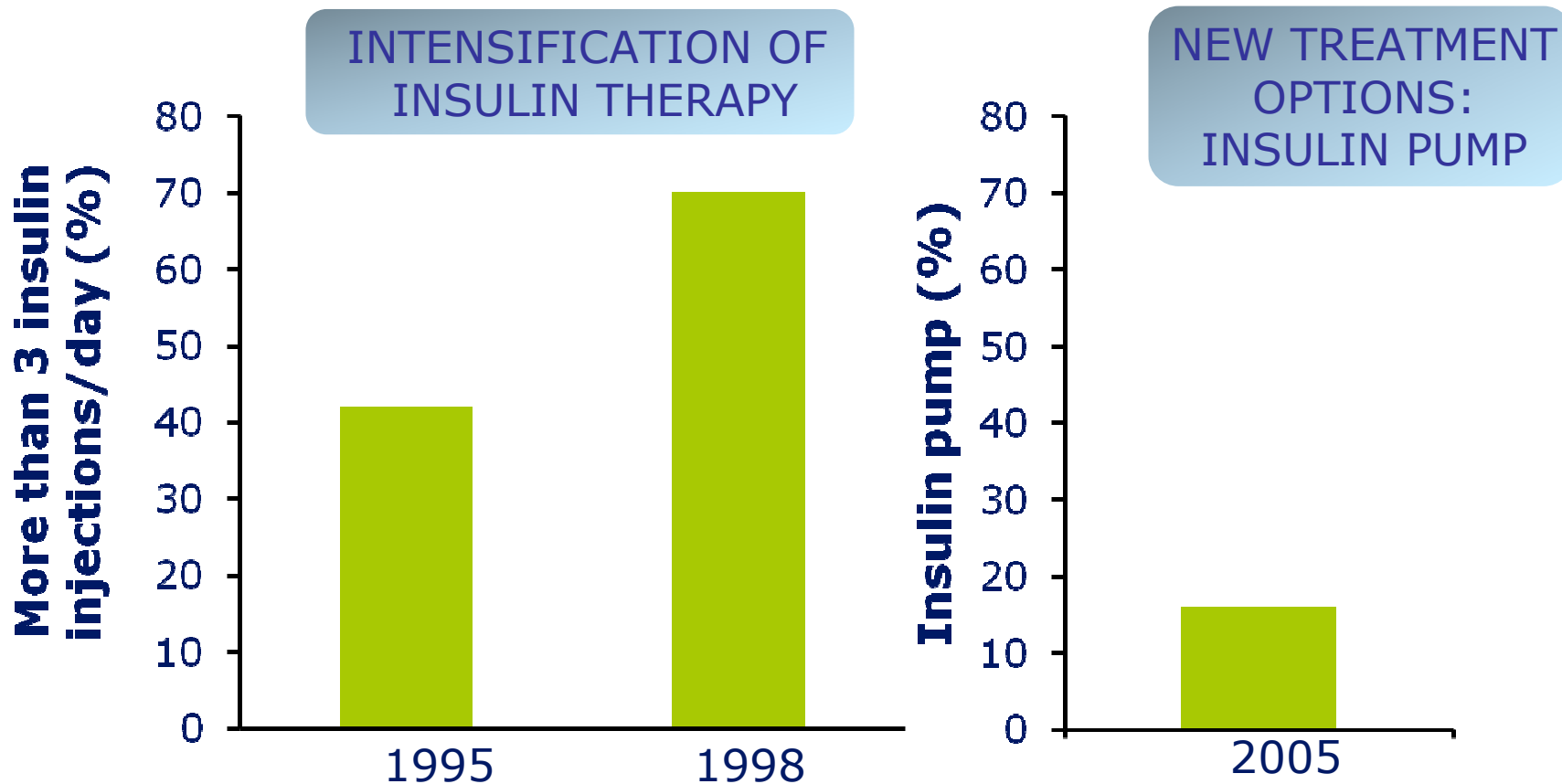


Despite major advances in management tools, metabolic control in children is suboptimal

International survey of childhood diabetes



Insulin therapy has been intensified and new treatment options have become available over the past 10 years



Data from Hvidøre study group

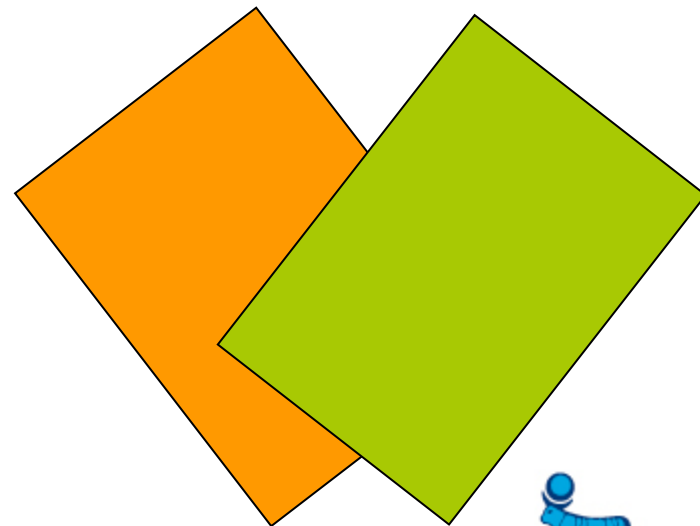


- Danne T & Hvidøre Group *Diabetes Care* 2001
- de Beaufort C & Hvidøre Group *Diabetes Care* 2007

Q: Do you think the average HbA_{1c} has decreased or increased over the same 10 year period

Vote **GREEN** if you think it decreased
Vote **ORANGE** if you think it increased

VOTE NOW!



The answer....

HbA_{1c} stayed the same

Metabolic control did not improve

WHY NOT?

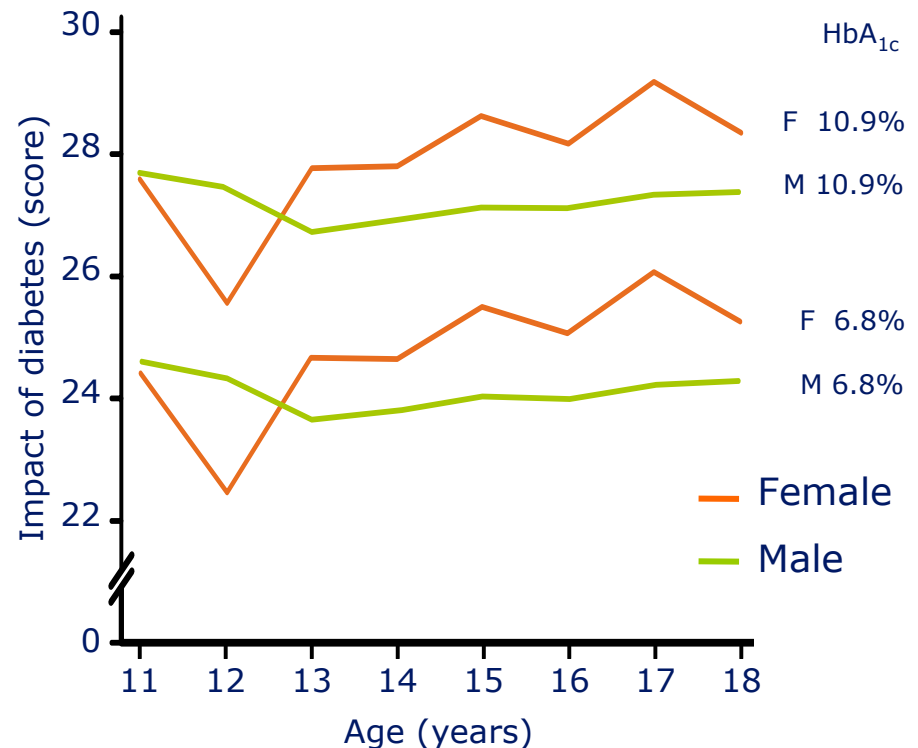
There must be other factors



Good child quality of life is associated with better metabolic control

Child QoL

- Deteriorated with age
- Poorer in females
- Poorer with high HbA_{1c}



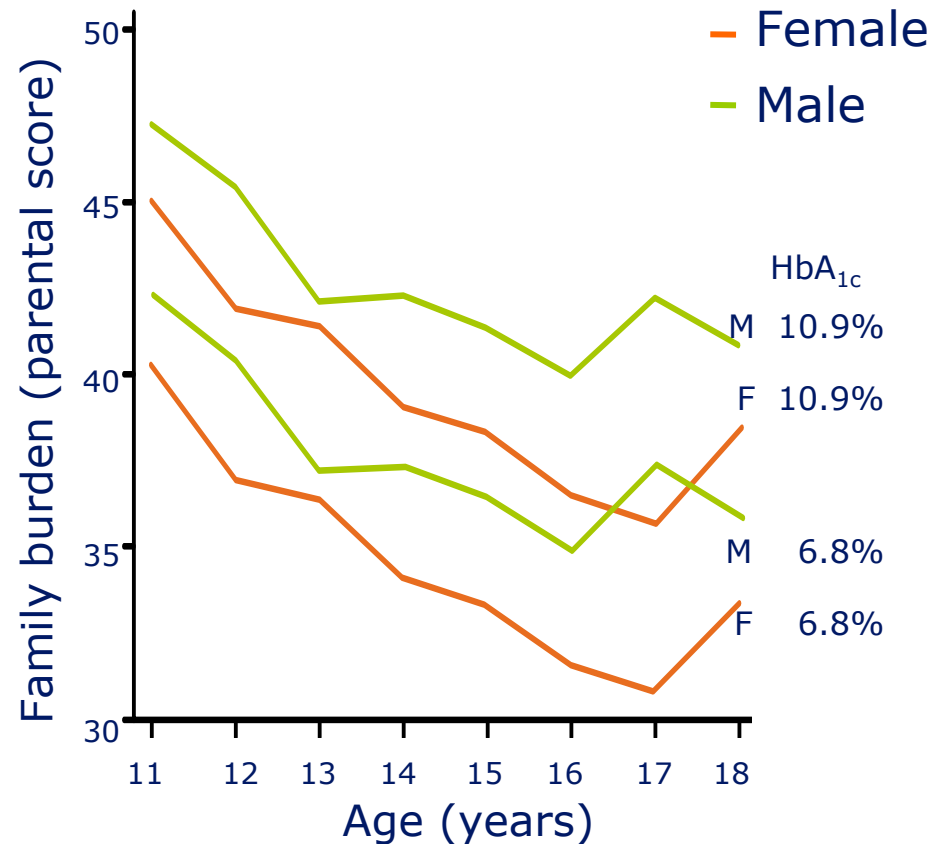
Impact of diabetes:
age, gender and HbA_{1c}



Parent perceived family burden is lower with better metabolic control

Family burden

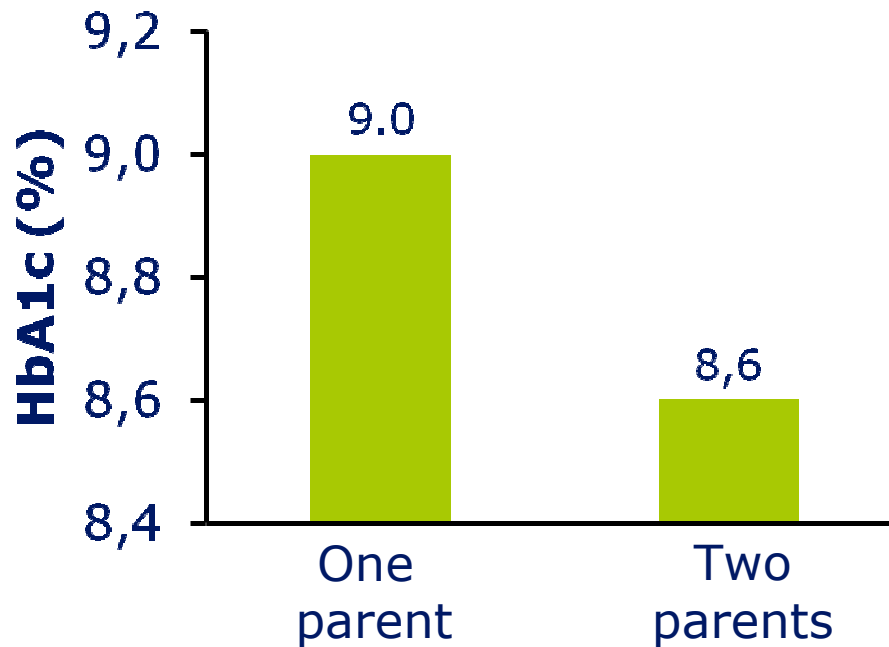
- Decreased with age
- Higher in males
- Different to adolescent perceptions
- Lower with better HbA_{1c}



Family burden and QoL: age, gender and HbA_{1c}



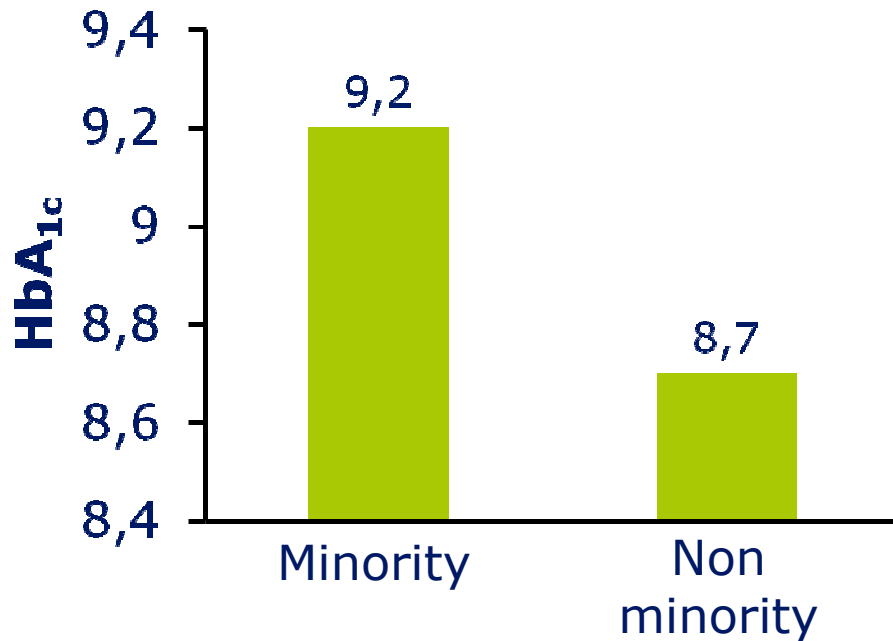
Metabolic control is poorer in single parent families



Perceived impaired child QoL		
	YES	NO
Child		✓
Parent		✓
Health care professional	✓	



Metabolic control is poorer in ethnic minorities



Perceived impaired child QoL		
	YES	NO
Child	✓	
Parent		✓
Health care professional		✓



Poor parent well-being is associated with poor metabolic control (WHO-5)

Parental well-being	Good	Poor	Depressed	<i>p</i> -value
HbA _{1c} (%)	8.1	8.3	8.5	<0.005



Parents living together have higher well-being scores

Parents	Parental well-being	HbA _{1c} (%)
Living together	65.6	8.1
Not living together	60.8	8.4
Adolescent does not know or see father	57.2	8.6



Poor parent well-being is associated with poor adolescent QoL

	Parental well-being		
	Good ≥ 51	Poor < 51	
Adolescent QoL	Mean	Mean	<i>p</i> -value
Adolescent-well being	12.1	10.7	0.001



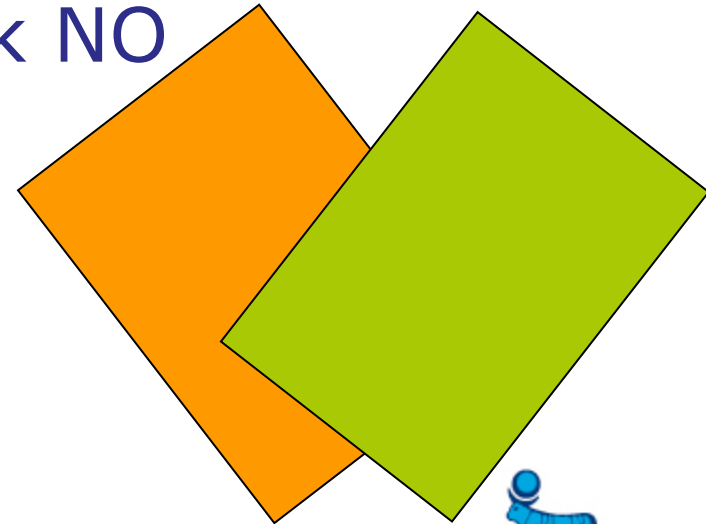
Generally adolescents dislike having parents involved in their activities

Q: Do you think parent involvement in diabetes care is good for metabolic control in adolescents?

Vote **GREEN** if you think YES

Vote **ORANGE** if you think NO

VOTE NOW!



Parent attendance at the diabetes clinic has a positive impact on HbA_{1c} and adolescent QOL

	Attending (n=1709)	Not attending (n=126)	
	Mean	Mean	<i>p</i> -value
HbA _{1c} (%)	8.1±1.3	8.6±1.8	<0.007
Adolescent-well being	11.9	9.8	<0.001



Assessment of parent over-involvement

How often are your parents:

- Too protective?
- Worry too much?
- Act as if diabetes was their disease?



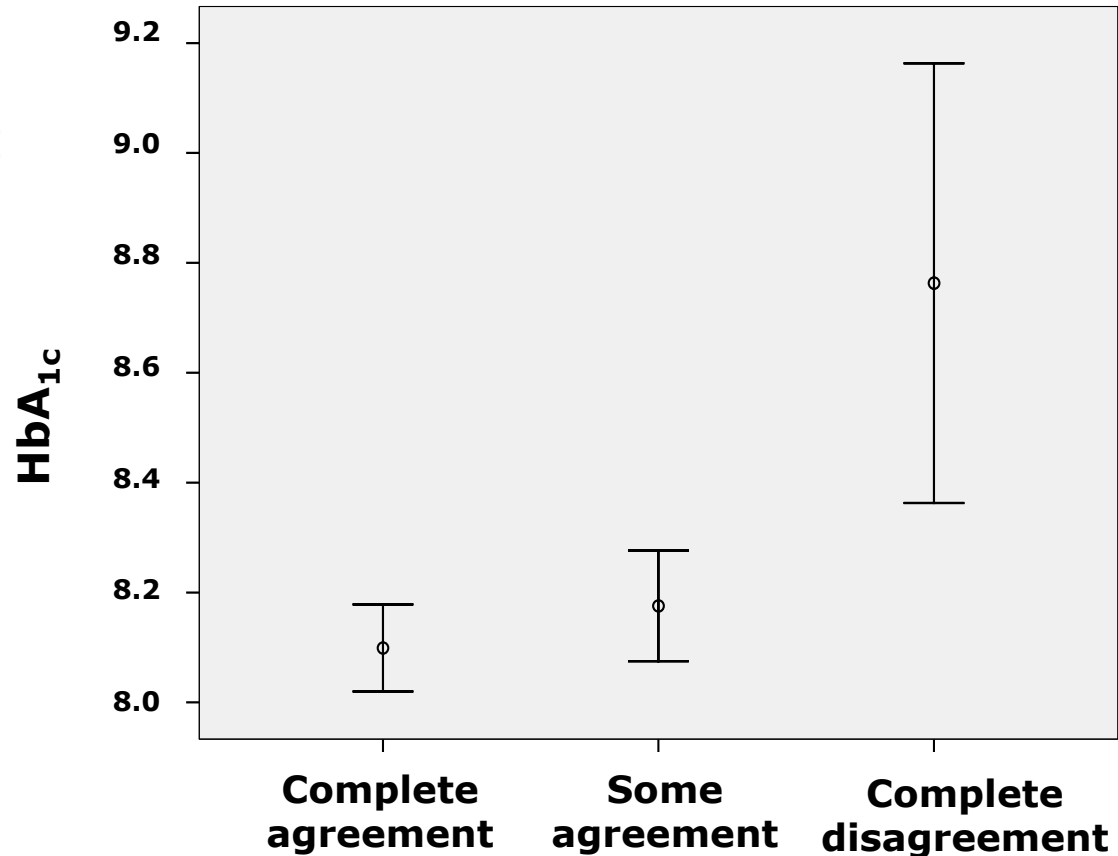
Parent over-involvement is associated with worse metabolic control & adolescent QoL

	Least over involved	Most over involved	
	Mean	Mean	<i>p</i> -value
HbA _{1c} (%)	8.0	8.3	<0.001
Adolescent-well being	12.4	11.1	<0.001



HbA_{1c} is higher when parents and adolescents disagree as to who is responsible for blood glucose testing

HbA_{1c} by parent-adolescent agreement for responsibility for remembering blood glucose testing

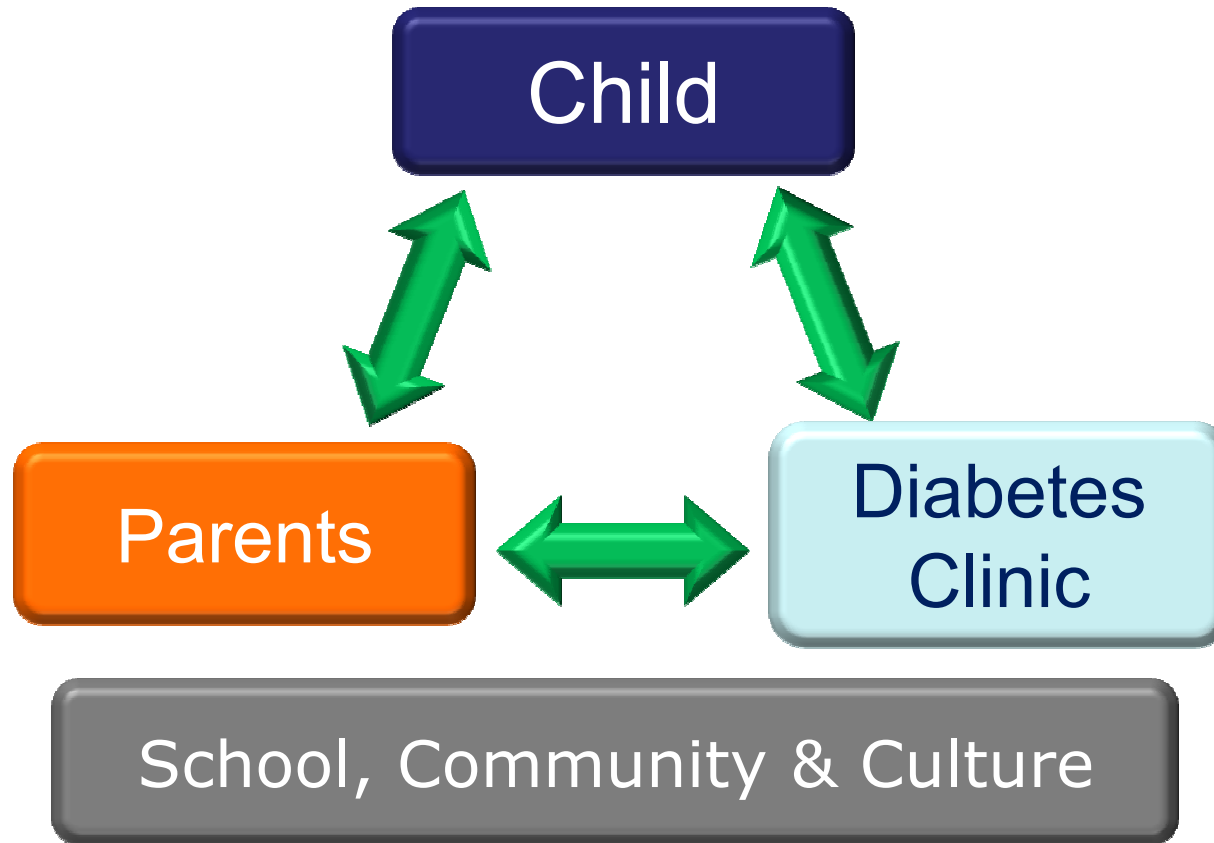


Summary: Psychosocial factors are associated with metabolic control

- Factors associated with metabolic control:
 - Child & adolescent QoL
 - Family burden and parent well-being
 - Family structure and ethnicity
 - Family dynamics
 - Health care team approach
- Psychosocial factors often not obvious to clinician
- Need scientific assessment & assumptions should be avoided



Diabetes management partnership



New paradigm for paediatric diabetes care – DAWN youth, ISPAD 2007, ADA 2008

In order to improve diabetes outcomes in children. The diabetes regimen should be:

- Tailored to the individual psychosocial needs of the child and family
- Provided by a multidisciplinary team trained in paediatric diabetes care



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